

## Post-traumatic stress disorder (update)

### Consultation on draft scope Stakeholder comments table

07 June 2016 – 05 July 2016

ID	Type	Stakeholder	Page no.	Line no.	Comments	Developer's response
1.	SH	Pottergate Centre	General	General	Dissociative Disorders and Complex PTSD need to be included in these guidelines with specific reference to treatment protocols which will be significantly different to primary PTSD.	<p>Thank you for your comment. Complex PTSD will be included in the guideline where there is available evidence.</p> <p>The effect of dissociative disorders on treatment of PTSD will be reviewed in the question relating to comorbidities.</p>
2.	SH	NHS England	General	General	No comments	Thank you.
3.	SH	Royal College of General Practitioners	General	General	<p>A thoughtful and comprehensive approach for a "hidden problem".</p> <p>There is a problem with definition and criteria of diagnosis, it is still the case that some Judiciary panels for asylum seekers who have been tortured not to accept PTSD as a medical diagnosis.</p> <p>The epidemiology and natural history is not well established, thus the identification of the especially vulnerable e.g. personality problems, anxiety/depression. Training is important for "at risk" groups like police, ambulance and health staff</p> <p>Human beings can and do recover-witness Auschwitz survivors who have been seen as saints, martyrs and celebrities but most PTSD has no such "glamour"</p> <p>Prevention rests on post trauma counselling and debriefing in an arena where there is neither blame nor shame.</p> <p>Treatment is not well proven by the RCT criteria and relies on clinical impression and anecdote. "Give sorrow words" seems to</p>	<p>Thank you for your comment.</p> <p>The guideline will not be covering the definition and criteria of diagnosis. The NICE surveillance report concluded that the introduction of DSM-V for adults is unlikely to have an effect on the current diagnostic recommendations. And that that there is currently a lack of data on validated screening tools. Whilst they acknowledged the impending release of ICD-11 will be significant, it is not due to be published until 2017/early 2018.</p> <p>The NICE guideline APMH covers trauma related to pregnancy.</p> <p>Please refer to the forthcoming NICE guideline on mental health problems in learning disabilities, (due mid-September), for guidance on the</p>

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					<p>be key and the ability to relive the experience in a “safe environment” and to try to defuse the anxiety and re-programme the emotional response to experiences which most humans find hellish. (PS)</p> <p>The draft scope does not specifically address PTSD in pregnancy, despite discussion at the scoping workshop. The RCGP feels that it should because there is scope for primary prevention by better care in pregnancy and postnatally, it is probably the commonest cause of PTSD in the UK, is not covered in NICE 192 (that merely refers to the previous PTSD guidance) and has consequences as women are faced with the prospect of the same recurrent experience in future pregnancies and there is scope for secondary prevention or additional/different care. (JS)</p> <p>Can the scope also include the diagnosis and treatment of PTSD in people with an intellectual disability? (MH)</p>	diagnosis and treatment of PTSD in people with intellectual disabilities.
4.	SH	Royal College of Paediatrics and Child Health	general	general	No comments	Thank you
5.	SH	Department of	general	general	No comments	Thank you

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		Health				
6.	SH	Royal College of Midwives	General	general	The RCM agrees with the content of the scope and has no further comments on the guideline update at this stage	Thank you
7.	SH	British Association for Psychopharmacology	General	-	It would certainly be worth examining the data for acute treatment (symptom reduction) and relapse prevention separately, for both psychological and pharmacological forms of intervention.	Thank you for your comment. We will address symptom reduction by looking at the effectiveness of both psychological and pharmacological treatment.
8.	SH	The Intensive Care Society	general	general	Critically ill patients include many people who may be subject to health inequalities: e.g. homeless people; people who have co-morbid substance misuse including alcohol use; and people with other health co-morbidities.	<p>Thank you for your comment. In the equality impact assessment we identified homeless people.</p> <p>People with coexisting conditions, including substance abuse, were also identified and will be explicitly considered in a review question on how to manage people with PTSD and a coexisting condition.</p> <p>As a result of your comment, the guideline has also been amended to include 'Critically ill patients' as an</p>

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						inequality issue
9.	SH	BeTr Foundation	General		Despite numerous revisions to the DSM criteria defining PTSD studies published during the different eras of changed criteria have been the evidence base upon which recommendations and treatment decisions have been made. To see over 10 years of recommendations being limited to CBT and EMDR shows a lack of initiative or concern for those suffering with PTSD. The RCT is not a gold-standard of research when its standards vary widely. For example, several authors have noted the lack of face-, content- and ecological validity in the two RCTs that reported potential harm in psychological debriefing that led to it being placed under the heading "Do Not Do". A lack of validity and no definition of harm in a protocol that, in its standardised form is practised in military, emergency and humanitarian aid agencies around the world with no reports of harm, weakens the authority of the RCT, the research teams, the reviewers and the evidence base upon which Guidelines are made.	Thank you for your comment. We will use the best possible evidence available, including any RCTs, to answer the review questions in the guideline and consider any potential harm associated with the treatments reviewed.
10.	SH	EMDR Association UK and Ireland	General	General	Psychological disorders continue to grow with significant impacts on health, society, human rights and economic consequences.  Eye Movement Desensitisation and Reprocessing (EMDR) is an evidenced based psychotherapy for Post -Traumatic stress disorder (PTSD) and other mental health conditions, that is empirically supported by over twenty four randomised control	Thank you for your comment. EMDR will be reviewed in this guideline

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					trials. Several meta analyses and international guidelines recommend EMDR therapy as a treatment of choice, specifically as a psychological trauma intervention. National Institute of Health and Clinical Excellence (NICE), 2005; International Society for Traumatic Stress Studies (ISTSS), 2008; The World Health Organisation (WHO) Guidelines 2013 on mental health and MH GAP intervention guide (2015). Further information in support of its treatment effects, can be found at the Francine Shapiro Library.	
11.	SH	Birth Trauma Association	General	General	<p>We would like to see the committee consider postpartum PTSD as a separate category within the guideline, for the following reasons:</p> <ul style="list-style-type: none"> <li>At the most conservative estimate, 1.5% of women experience PTSD after giving birth (some estimates go as high as 8%, with other studies suggesting that the proportion of women with some PTSD symptoms is 30%). This conservative estimate translates into 10,000 new cases of postpartum PTSD a year in England and Wales. Assuming that untreated PTSD symptoms typically last three years (though again, estimates vary), that translates into 30,000 cases at any one time. It seems likely that, in England and Wales, women with postpartum PTSD represent the single biggest category of people suffering from PTSD.</li> </ul>	Thank you for your comment. Trauma associated with childbirth has been reviewed in the APMH NICE guideline and we will refer to their recommendations.

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					<ul style="list-style-type: none"> <li>• While health professionals are increasingly alert to the possibility of PTSD in other groups, such as victims of violence or sexual abuse, there is still little awareness of postpartum PTSD. Mental health problems after childbirth are often assumed to be postnatal depression, a diagnosis that can be positively harmful for some women with PTSD. While the Edinburgh scale is routinely used to diagnose PND after childbirth, there is no equivalent scale to diagnose PTSD. Treating postpartum PTSD as a separate category within the guideline is an important way of bringing the condition to the attention of medical professionals.</li> <li>• New mothers have a particular set of circumstances that differentiate them from other PTSD sufferers:               <ul style="list-style-type: none"> <li>- They may be breastfeeding, which means that drugs used to treat other cases of PTSD may not be appropriate. (We are aware that the current NICE guideline does not recommend drug treatments for PTSD unless it is comorbid with severe depression, or talking therapies are refused, but it is possible that this may change.)</li> <li>- While suffering from distressing mental health problems, mothers with postpartum PTSD have to take on the heavy responsibility of caring for a newborn baby – something that is stressful even for parents who are</li> </ul> </li> </ul>	

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					<p>mentally well. Some mothers with postpartum PTSD fail to bond with their baby, while others experience symptoms of extreme anxiety (hypervigilance) about the baby. This may have consequences for the wellbeing of the baby and for the sustainability of the parents' relationship, leading to greater pressure on the NHS and other public services.</p> <ul style="list-style-type: none"> <li>- PTSD sufferers typically exhibit avoidance behaviour. While most sufferers of non-complex PTSD can take steps to avoid reminders of the trauma, the baby is a constant reminder of the trauma for sufferers of postpartum PTSD. Women with postpartum PTSD may also avoid contact with health professionals (with possible consequences for their own health and that of their baby) and with other mothers, usually a source of support in early parenthood. As a result, they may feel even more isolated than other sufferers of PTSD, exacerbating the condition. We hope the guideline could look at ways of addressing this.</li> <li>- Extreme anxiety can make some women fear that their baby may be taken into care if they admit to any mental health issue, and they avoid seeking treatment.</li> </ul> <p>While we recognise that PTSD has features common to all categories of sufferers, we believe that the particular</p>	

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					circumstances of women with postpartum PTSD necessitate separate consideration and that health professionals need to aware that a traumatic birth might trigger PTSD.	
12.	SH	Royal College of Nursing	general	general	No comments	Thank you.
13.	SH	Freedom From Torture	General	General	<p>Freedom from Torture (FFT) is a UK-based human rights organisation and one of the world's largest torture treatment centres. We are the only organisation in the UK dedicated solely to the care and treatment of survivors of torture and organised violence. Since our foundation in 1985, more than 56,000 people have been referred to us for rehabilitation and other forms of care and practical assistance. We currently have over one thousand clients in treatment at our centres in London, Manchester covering the North West of England, Newcastle covering the North East of England, Birmingham covering the West Midlands and Glasgow covering the whole of Scotland. We strongly welcome the updating of the NICE Guidelines on Post Traumatic Stress Disorder (PTSD) and are delighted to have this opportunity to respond to NICE's draft scope.</p> <p>Our submission draws on over 30 years of clinical experience as a specialist torture rehabilitation centre and our response below has been developed at a multidisciplinary roundtable comprising service users, internal clinical staff including physiotherapists,</p>	Thank you. We will be considering other areas of care besides treatment, including coordinating care and support for family and carers.

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					<p>psychologists, psychiatrists, and external experts.</p> <p>We believe that the issues relating to the treatment of survivors of torture under the current guidelines are widespread and complex and go beyond the question above of which interventions could lead to cost savings. Our submission does cover this but we also comment on the full range of issues as we see them.</p>	
14.	SH	Freedom From Torture	General	General	<p>It is our contention that survivors of torture are one of several groups disadvantaged under the current 2005 NICE Guidelines on PTSD:</p> <ul style="list-style-type: none"> <li>▪ The unique experiences of survivors of torture and other complex trauma are omitted from the NICE Guidelines on PTSD;</li> <li>▪ As a result, PTSD in survivors of torture may be missed or misdiagnosed, access to appropriate treatment for survivors of torture may be withheld in a discriminatory way, or be inappropriate;</li> <li>▪ A denial of appropriate treatment for survivors of torture is not only discriminatory and reneges on our duty to rehabilitate torture survivors, but risks re-traumatisation and is costly to the NHS and social services</li> </ul>	<p>Thank you for your comment. We will be addressing complex trauma as well as interventions for survivors of torture in the updated PTSD guideline where there is available evidence.</p> <p>The guideline will not be covering the diagnosis of PTSD. The NICE surveillance report concluded that the introduction of DSM-V for adults is unlikely to have an effect on the current diagnostic recommendations and that that there is currently a lack of data on validated screening tools. Whilst they acknowledged the impending release of ICD-11 will be significant, it is not due</p>

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						to be published until 2017/early 2018.
15.	SH	Freedom From Torture	general	general	Asylum seekers/refugees may share certain common characteristics with torture survivors. For those asylum seekers/refugees that experienced past persecution <sup>1</sup> , by definition <sup>2</sup> this is likely to have been directly targeted owing to the victim's race, religion, nationality, membership of a particular social group [e.g. sexual orientation or gender identity], or political opinion. However, there is a particular and specific personalisation and intentionality of torture which goes beyond ill-treatment that the Guidelines should recognise; not only is it not accidental or randomised, but it is also intended to dehumanise, degrade, destroy and silence. Child sexual abuse, domestic violence and other forms of trauma are also personal, targeted and deliberate, but by definition torture <sup>3</sup> is used as a tool of oppression by those in state power, and thus survivors are unable to approach the authorities for protection. The	Thank you for your comment. We will consider carefully the treatment of people who experience PTSD including those who have been victims of torture, asylum seekers and refugees where there is available evidence available for the guideline committee to make recommendations.

<sup>1</sup> The Refugee Convention is 'forward looking' that is based on a fear of persecution; there is no requirement of past persecution

<sup>2</sup> UNHCR (1951), [Text of the 1951 Convention Relating to the Status of Refugees Text of the 1967 Protocol Relating to the Status of Refugees Resolution 2198 \(XXI\) adopted by the United Nations General Assembly](#), Article 1

<sup>3</sup> UN (1984), [Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment](#),

Adopted and opened for signature, ratification and accession by General Assembly resolution 39/46 of 10 December 1984 entry into force 26 June 1987, in accordance with article 27 (1), Article 1

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					profound nature of torture can be understood as an existential as well as relational trauma. <u>It should also be noted as one survivor explains "my understanding of torture is different to everyone else's. It's very difficult to explain. Everyone's experience is unique to them. Survivors of torture are all different".</u>	
16.	SH	Freedom From Torture	general	general	The Guidelines should recognise that torture impacts individuals on multiple levels; it fragments identity and causes feelings of shame, guilt and responsibility. <u>One of our service users described the feelings of guilt she felt as follows, "you are the cause of the torture so if your asylum case is refused, it is a consequence of what you've done- it's your fault".</u> Torture has the effect of destroying the survivor's trust in those who are meant to protect them. Sexual violence may compound shame and pregnancies as a result of rape add further complexities, especially as births from these pregnancies can be traumatising. There is also a resulting accumulation of losses intertwined with forced flight that torture survivors in the UK may experience; a loss of homeland, home, family, social network, job, language, immigration status, etc. which can all be traced back to the experience of torture. Many will have suffered additional losses (e.g. close family members) and many will be facing very significant ongoing difficulties likely to affect their mental health such as physical health problems, poverty, unemployment, poor	<p>Thank you for highlighting that not accessing service's is a concern when treating people with PTSD.</p> <p>This may addressed when we consider what factors can influence or improve access to effective treatment</p> <p>To address the social isolation, there is also a review question on what practical and social support should be made available to families and carers of people with PTSD?</p>

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					housing, racism, separation from family etc. <sup>4</sup> In the new Guidelines there should also be a recognition of the impact of social isolation on torture survivors, and that survivors may feel less safe in displacement. Torture survivors often also encounter problems with disclosure <sup>5</sup> , accessing/engaging with services, language issues and access to interpreters. In addition, survivors are unlikely to secure justice or reparations, especially in displacement.	
17.	SH	Freedom from Torture	general	general	Survivors are likely to experience an amalgamation of physical and psychological sequelae which may include persistent and high levels of pain and/or unexplained pain and be difficult to verbalise. Torture survivors may experience dissociation, depression, anxiety, personality change, psychotic experiences, mutism /selective mutism, high levels of suicidal thinking, on top of the nightmares, flashbacks, intrusive thoughts and other symptoms of PTSD. The multifaceted, pervasive and ongoing nature of multiple traumas should be recognised, as should the risk of relapse and that recovery may not be linear. <u>This is exemplified by one of our service users who explained that “I know what it is to be traumatised. It feels like a life time</u>	Thank you for your comment. We have included in the guideline the following question that will address the psychological sequelae:  “For people with PTSD who present with one or more coexisting conditions, should treatment for PTSD differ from treatment for those without a coexisting condition, and what is the best way to address these differences when delivering and coordinating care?”

<sup>4</sup> Freedom from Torture (July 2013), [The Poverty Barrier: The Right to Rehabilitation for Survivors of Torture in the UK](#)

<sup>5</sup> Bogner, D., Herlihy, J. & Brewin, C. R. (2007), [Impact of sexual violence on disclosure during Home Office interviews, British Journal of Psychiatry](#), 191, 75-81

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					<u>experience that goes on and on</u> ".	We agree that physical sequelae are an important facet of the experience of people with PTSD, however they will not be addressed by this guideline; instead we will refer practitioners to the relevant existing NICE guidelines.
18.	SH	Freedom From Torture	general	general	We also recommend that the new Guidelines further consider the cultural expression and denial of torture and explain that children and separated young people are impacted differently from adults by the experience of torture. Children's threshold of emotional and physical pain is different to that of an adult. Our clinical experience shows that experiences of torture and organised violence are likely to affect the physical, emotional and neuro-biological development of children and young people by delaying development or rendering it uneven. Thus chronological age may not be consistent with developmental age and this needs to be taken into account when assessing young torture survivors and designing and delivering rehabilitation services for them. Separated children might be coping with the loss of a parent, not knowing the whereabouts of a parent, a missing parent or sibling and not have stable figures in their life. It should be recognised that is often the case that family honour takes precedence over safety, protection and rehabilitation following torture and this can be a powerful barrier,	<p>Thank you for highlighting that accessing care is a concern for treating women, young people and children with PTSD.</p> <p>This may be addressed when we review the question: "For adults, children and young people with clinically relevant post-traumatic stress symptoms, what factors should be taken into account in order to provide optimal care across all conditions and coordination of care?"</p> <p>Although language and culture will not specifically be covered by this update, cultural factors relevant to service access, such as those that you</p>

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					especially for women and children, to accessing rehabilitation services.	describe, will be considered as part of review question 3.1: "For adults, children and young people with clinically relevant post-traumatic stress symptoms, what factors should be taken into account in order to provide optimal care, coordination of care and access to care?"
19.	SH	Freedom From Torture	General	General	The definition of PTSD in the current NICE Guidelines is focused on a single incident of trauma (such as a traffic accident) which only account for a small proportion of PTSD sufferers and which excludes survivors of torture. A survivor of torture will often have been exposed to multiple traumatic events stretching over many years – an Afghani survivor may have witnessed multiple atrocities as a child (bombings, attacks on their village) and been forcibly displaced several times before perhaps two, three or more episodes of detention and torture as an adult, followed by a long, difficult and dangerous journey to the UK to seek asylum: the nightly news is full of reports of refugees drowning in the Mediterranean or the appalling conditions in the Jungle in Calais. <sup>6</sup> Each new traumatic event	Thank you for your comment. We will be including complex PTSD and situations where people have experienced multiple traumas

<sup>6</sup> International Organisation for Migration (as of 4 July 2016), [Missing Migrants Project](#), Retrieved 05.07.2016 at 09.34  
Clare Moseley, Guardian Newspaper (3 March 2016), [Sorry, France, but razing the Calais 'Jungle' is not humanitarian](#)

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					<p>will remind the survivor of previous events: the psychological and physiological responses to both will collide within the person's mind and nervous system, magnifying the reaction to each: if you are already frightened and in pain, another frightening and painful event will add to both.</p> <p>Survivors of torture often report a profound sense of an altered self, an experience far beyond the symptoms listed within PTSD: a state of doubt and existential terror regarding their place in the world, safety and relationships with others, as well as severe distress and a service assisting this group psychotherapeutically needs to understand the implications of this condition.</p>	
20.	SH	Freedom From Torture	general	general	<p>Complex PTSD is understood as describing the experience of survivors of childhood sexual abuse and prolonged domestic violence, as well as war, genocide or torture and is more prevalent among the clients presenting to Freedom from Torture than PTSD alone. A recent survey of one North London NHS Trauma Clinic, found that 66% of patients reported having been tortured.<sup>7</sup> Whilst the DSM V<sup>8</sup> does not include complex PTSD, the World Health Organization (WHO) Working Group on the Classification of Stress-Related Disorders has proposed the</p>	<p>Thank you for your comment. We will be including the treatment of PTSD and, where there is evidence available, complex PTSD.</p>

<sup>7</sup> *Freedom from Torture (2016), Audit of prevalence of torture among patients of a North London Trauma Clinic. Unpublished.*

<sup>8</sup> American Psychiatric Association (2013), *Diagnostic & Statistical Manual of Mental Disorders*

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					<p>inclusion of Complex PTSD as a new diagnosis related to but separate from PTSD.<sup>9</sup> The World Health Organisation ICD 11 (International Classification of diseases, 11<sup>th</sup> Edition) are due by 2018 and it is recommended that the NICE Guidelines be streamlined to reflect amendments to ICD-11.</p> <p>Table One shows the additional areas of traumatic experience present in Complex PTSD, in addition to those present in PTSD<sup>10</sup>:</p> <table border="1"> <thead> <tr> <th>PTSD</th> <th>Complex PTSD</th> </tr> </thead> <tbody> <tr> <td></td> <td>Interpersonal Disturbances</td> </tr> <tr> <td></td> <td>Negative self-concept</td> </tr> <tr> <td></td> <td>Affect dysregulation</td> </tr> <tr> <td>Sense of Threat</td> <td>Sense of Threat</td> </tr> <tr> <td>Avoidance</td> <td>Avoidance</td> </tr> <tr> <td>Re-experiencing</td> <td>Re-experiencing</td> </tr> </tbody> </table>	PTSD	Complex PTSD		Interpersonal Disturbances		Negative self-concept		Affect dysregulation	Sense of Threat	Sense of Threat	Avoidance	Avoidance	Re-experiencing	Re-experiencing	
PTSD	Complex PTSD																			
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	Affect dysregulation																			
Sense of Threat	Sense of Threat																			
Avoidance	Avoidance																			
Re-experiencing	Re-experiencing																			

<sup>9</sup> Maercker et al., (2013) (cited in Marylène Cloitre, Donn W. Garvert, Brandon Weiss, Eve B. Carlson and Richard A. Bryant (2014) (European Journal of Psychotraumatology), [Distinguishing Complex PTSD, and Borderline Personality Disorder: A latent class analysis](#), Received: 3 June 2014; Revised: 22 July 2014; Accepted: 18 August 2014; Published: 15 September 2014)

<sup>10</sup> European Journal of Psychotraumatology (2013). 4 20706 (cited in [TraumaDissociation.com](#); Retrieved 20.06.16 at 13.33.)

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21.	SH	Freedom From Torture	General	General	<p>Interpersonal problems include “social and interpersonal avoidance (avoiding relationships), feeling distance or cut off from others, and never feeling close to another person.” Negative self-concept involves feelings of worthlessness and guilt or an absence of a sense of the self. This can include a fragmented sense of self with Dissociative Identity Disorder. Interpersonal Sensitivity includes relationship difficulties, caused by unexpressed anger or rage at the perpetrators. “Affect Dysregulation” includes being unable to manage one’s own emotions and can manifest as self-destructive behaviour.<sup>11</sup> Complex PTSD and Enduring Personality Change were excluded from the 2005 Guidelines due to a lack of research evidence about both conditions at the time. We hope that the upcoming review will consider these in detail and draw upon the testimony and experience of survivors of torture, childhood sexual abuse and prolonged domestic violence amongst others in developing guidance on the treatment of these conditions. In particular, we hope that the work of the International Classification of Diseases (which, as noted, covers both) will be considered.</p>	<p>Thank you for your comment. We will include complex PTSD where there is available evidence.</p> <p>PTSD may precede enduring personality change and will be considered if there high quality data available.</p> <p>For treatment of PTSD we will be including high quality RCT evidence in the first instance, should there be no such evidence we will consider other forms of evidence. .Patient experience will be considered for questions such how to improve the delivery of care to those with PTSD. Service users on the guideline committee whose experience will help shape the recommendations.</p>

<sup>11</sup> Traumadissociation.com (Jul 01, 2016; Retrieved Jul 1, 2016 at 10.28), [Complex Post-traumatic Stress Disorder](#)

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22.	SH	Freedom From Torture	General	General	<ul style="list-style-type: none"> <li>▪ PTSD in survivors of torture may be missed or misdiagnosed</li> </ul> <p>As the previous section details, survivors' problems are not necessarily defined or discrete enough to 'categorise' and therefore might not fit neatly into the current definition of PTSD. Survivors might not present with classic symptoms of PTSD, but with other emotional, social, behavioural problems, some of which are culturally defined and thus have the potential of being lost in the medical model.</p> <p>Torture survivors' symptoms can be common to other problems such as depression, anxiety, dissociative disorder and as a result a survivor of torture may not be diagnosed with PTSD and therefore not be getting help for the serious trauma they have experienced. For example, survivors have spoken of experiencing hallucinations), such as seeing soldiers in the room, which could be better understood as cultural responses to trauma, not psychotic experiences. One client we worked with, despite her history of trauma and torture was known by the Community Mental Health Team (CMHT), was still inappropriately referred to a specialist personality disorder service which caused her considerable distress.</p> <p>Current diagnostic tools are culturally biased and validation tools may also not be available in other languages. For example, it is a presumption that PTSD symptoms need to show up within six</p>	<p>Thank you for your comment.</p> <p>The current PTSD guideline addresses the importance of acknowledging people with PTSD treated in the NHS come from diverse and ethnic backgrounds and provide recommendations to address potential barriers.</p> <p>Thank you for highlighting that people may still respond to treatment many years post-trauma. We will take this into account in developing our recommendations.</p>

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				2005 Guideline , section: 2.3.1	months but for survivors focused on survival and embarking on a journey to and starting a life in the UK who experience for example a fear of return and/or immigration detention, a mistrust/fear in state authority, language and cultural barriers, symptoms could present much later. The Guidelines should provide explanations of non-western understandings of trauma and responses to trauma or expressions of distress. They should also recognise that many of our clients present to services many years post-trauma and may still benefit from psychological treatment.	
23.	SH	Freedom From Torture	General	General	It is also our experience that survivors of torture may present with symptoms that are too complex for Improving Access to Psychological Therapies (IAPT) services, but may not meet the threshold for CMHT, with the result that they don't receive any treatment for the trauma they've experienced. We therefore recommend that the new PTSD Guidelines should incorporate the unique experiences of survivors of torture as well as the range of emotional and behavioural problems survivors of torture suffer from in order to assist in appropriate diagnosis and therefore appropriate treatment.	Thank you for your comment. We will consider this issue when considering issues such as promoting access to treatment
24.	SH	Freedom From Torture	General	General	<ul style="list-style-type: none"> <li>▪ Access to appropriate treatment for survivors of torture may be withheld in a discriminatory way, or be inappropriate</li> </ul>	Thank you for highlighting that not accessing care is a concern for treating people with PTSD.

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				2005 Guideline , section: 10.5	<p>Whilst the current PTSD Guidelines may not set out to address the specific treatment needs of torture survivors, it is our experience that in the absence of other guidance, they are being used to determine treatment for torture survivors, which for the reasons elucidated below, may be discriminatory or inappropriate.</p> <p>Section '10.5 Working with refugees and asylum seekers' suggests that a Three Phased Model of therapy be deployed for these groups, that the approach should be focused on the individual rather than on the service, which may mean offering a holistic, integrated approach within one setting. Freedom from Torture agrees with this approach and operates a Three Phased Model of rehabilitation, as described by Judith Herman<sup>12</sup> among others. We contend that the Guidelines should explain that this approach is relevant to survivors of torture and other complex trauma and not limited to the treatment of asylum seekers/refugees. For the reasons detailed above, it should be recognised that whilst survivors of torture may also be seeking asylum in the UK or have been awarded refugee status, it is their experience of torture that identifies them as a group, not their immigration status.</p> <p>We are concerned that loose and ambiguous wording in section</p>	<p>This may addressed when we review the question: "For adults, children and young people with clinically relevant post-traumatic stress symptoms, what factors should be taken into account in order to provide optimal care and access across all conditions and coordination of care? It may lead to a revision of the 2005 guideline.</p>

<sup>12</sup> Judith Herman (2015), *Trauma and Recovery: The Aftermath of Violence--From Domestic Abuse to Political Terror*

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					10.5 has been interpreted by service providers to deny treatment to torture survivors in practice.	
25.	SH	Freedom From Torture	General	General	The Guidelines rightly emphasise the need to first stabilise a client before trauma therapy is begun, stressing the appreciation of individual circumstance and that building a trusting relationship should be a priority of Phase 1. The Guidance states that trauma focused therapy should be considered once the individual has "achieved a sufficient sense of stability and security". However, we are concerned that the original meaning of 'stabilisation' of Phase 1 has been wrongly interpreted by service providers who equate 'stability' with securing refugee status and thus use the Guidelines to deny survivors of torture appropriate treatment whilst their asylum case is being processed.	Thank you for highlighting this. We will consider this point carefully in developing the new guideline and seek to remove any ambiguity in the updated guideline.
26.	SH	Freedom From Torture	General	General	While there are many excellent examples of NHS psychological therapy services engaging with survivors of torture who are still seeking asylum, there are other services who will refer asylum seekers out routinely. In 2015, 57% of the circa one thousand referrals for treatment which Freedom from Torture received were from NHS Services. Many were thoughtful, appropriate referrals from colleagues who fully understood the needs of the client and the limitations of the models they worked within: many stated that the client had complex psychological and social needs, requiring a long-term holistic intervention of the type	Thank you for your comment. We will carefully consider the wording of the recommendations in the guideline in the light of your comment and do so in the context of current legislation for the care and treatment of asylum seekers.

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					Freedom from Torture offers and unavailable within the eight or twelve week model their service offered. Others were less considered: we have been informed by some NHS Mental Health Services around the country that they do not treat asylum seekers as a matter of policy "because that's what the NICE Guidelines say". Referrals from IAPT services in the West Midlands have stated that they cannot accept asylum seekers as clients as they are an 'unstable population' on the basis that they do not have permanency in the UK. If this criteria was extended to other populations lacking permanency, then the homeless would be excluded from treatment too, another of society's most vulnerable groups.	
27.	SH	Freedom From Torture	General	General	<u>One of our traumatised clients told us that after she was turned away from her GP, she ended up in hospital. She was asked to fill out a questionnaire on her symptoms, but because she didn't self-harm or have suicidal ideation, she was denied any treatment. She was told "you're not traumatised, you have an immigration problem". Her impression was "They only pay attention if you are shouting, when you have very severe symptoms. They want you to get worse before you get treatment. There are lots of people going through that".</u>	As previously stated we will carefully consider the wording of the recommendations in the guideline in the light of your comment and do so in the context of current legislation for the care and treatment of asylum seekers.
28.	SH	Freedom From Torture	General	General / 2005	The Guidelines are being used to deny asylum seekers treatment despite the fact that they do not state that it is never	As previously stated we will carefully consider the wording of the

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				Guideline , section: 10.5	possible to engage therapeutically with an asylum seeker. Section 10.5 states that in depth therapeutic work <i>may</i> be impossible 'if the PTSD sufferer faces a realistic prospect of being returned to face more trauma'. However, our experience, based on thirty years of clinical experience with this client group and the testimony of the survivors we work alongside, is that it is perfectly possible to engage therapeutically with a survivor of torture who is still in the asylum system.	recommendations in the guideline in the light of your comment and do so in the context of current legislation for the care and treatment of asylum seekers.
29.	SH	Freedom From Torture	General	General	In the first or "Stabilisation" stage of rehabilitation, we engage in addressing the survivor's practical, external world issues (finding somewhere to live, accessing good legal advice, meaningful daytime activity, building a support network, management of pain and psycho-education), within a trusting relationship. This can help the survivor reach a place where they are ready to tell us their story and reduce the power of the overwhelming memories in the second or Narrative Phase. The third phase concerns connection with the community and broader society and building a future. We work with clients individually and in groups which include activity based groups such as music, bread making, gardening and football as well as more traditional psychotherapeutic groups: torture is used by states to silence dissidents, thinkers, those who look, believe or behave differently and to suppress freedom of expression. Many survivors are left unable to speak directly of what happened to	Thank you for your comment. Where we find evidence for the phased approach you set out we will carefully consider it.

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					them so we deploy alternatives to help them find a medium of expression. Sadly, our caseload includes many children affected by torture, either directly experiencing it themselves or through the torture of their parents and we engage with families systemically and with separated children as well, around their trauma and the impact of torture on their development.	
30.	SH	Freedom From Torture	General	General	We recommend that the Guidelines make explicit how the refugee status determination process itself can be a stressor. For many torture survivors, so long as there is a risk of return home to further torture, the traumatic experience is not over. For this reason, dealings with government officials at mandatory regular reporting or at asylum interviews or appeal hearings, which require the survivor to give a detailed account of his or her torture experience may cause unacceptably high levels of subjective distress or even trigger flashbacks, during which past and present collide and the survivor re-experiences the torture. Being held in detention and tortured renders the victim helpless and powerless at the time, feelings exacerbated by the stress of passing through the asylum application process in the UK, particularly given long delays, feelings of/being disbelieved and receiving negative decisions as well as the possibility of being detained in an Immigration Removal Centre. Survivors for whom the fear of return is overwhelming may be at risk of self-harm including attempted suicide, as a means of avoiding further persecution, torture or being put to death. Survivors living in	Thank you for your comment. We will consider your comments when developing the recommendations for this guideline

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					exile, and their families, are therefore often at their most vulnerable during the periods in which their asylum claim is pending or refused.	
31.	SH	Freedom From Torture	General	General	<p>However, by withholding any treatment from survivors during the process of claiming asylum, there is both the risk that PTSD symptoms will get worse or pushed to crisis, but also that the insecurity of their immigration status triggers new psychological trauma. Clients have described this uncertainty to us as “<i>a new mental torture</i>”.</p> <p>Excluding survivors of torture from appropriate therapeutic care whilst their asylum claim is being decided is not only discriminatory, it contravenes the UK's obligations under Article 14 of the UN Convention Against Torture which sets out the right to rehabilitation.<sup>13</sup> In November 2012 the Committee issued a ‘General Comment’ on the Implementation of Article 14 by States parties which affirms that rehabilitation should be holistic, integrated, appropriate, promptly accessible without</p>	Thank you for your comment. Asylum seekers are eligible for access to NHS Mental Health Services around the country. As previously stated we will look carefully at our recommendations to ensure that they cannot be misinterpreted and so impact negatively on access to PTSD treatment for asylum seekers.

<sup>13</sup> UN (1984), [Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment](#),

Adopted and opened for signature, ratification and accession by General Assembly resolution 39/46 of 10 December 1984 entry into force 26 June 1987, in accordance with article 27 (1), *Article 1*

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					discrimination and regardless of the victim's identity including being asylum seekers or refugees. <sup>14</sup> The importance of ensuring that asylum seeking torture survivors and minors who have been victims of torture have access to rehabilitation services is also recognised in the 2003 EU Qualification Directive laying down minimum standards for the reception of asylum seekers <sup>15</sup> which the UK is a signatory to. <sup>16</sup> The NHS also has a duty of care to survivors. The Department of Health identifies survivors of torture among the groups exempt from NHS charges (for treatment required for a physical or mental condition caused by torture), that treatment for torture survivors should be holistic and that there are significant complexities in identifying this group of vulnerable people. <sup>17</sup>	
32.	SH	Freedom From Torture	General	General	We are also concerned that one impact of the NICE Guidelines not explicitly addressing the treatment of survivors of torture, but instead only briefly covering this in a section on refugees and	We will consider all available high quality evidence on how to optimise treatment for people with PTSD,

<sup>14</sup> UN Committee against Torture, (19 November 2012), [General Comment No. 3 of the Committee against Torture Implementation of article 14 by States parties](#), Articles 11-15

<sup>15</sup> [EU Council Directive 2003/9/EC of 27 January 2003 laying down minimum standards for the reception of asylum seekers](#)

<sup>16</sup> N.B. This was recast in 2013 but the UK opted out of adopting the new Directive

<sup>17</sup> Department of Health (2015), [Guidance on implementing the overseas visitor hospital charging regulations 2015, Sections 7.3-7.5](#)

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					asylum seekers is that their specific treatment needs may be overlooked and that trauma focused treatment therapy may be offered in isolation before stabilisation phase 1 has been achieved. We want to stress that rehabilitation for survivors of torture goes far beyond symptom reduction and single modalities of treatment, such as the 8-12 sessions of trauma based CBT that is recommended for adults in the current NICE Guidelines. Freedom from Torture clinicians deploy a wide range of modalities, according to their training and the needs and preferences of the survivor and in the survivor's language, which now includes EMDR, CBT and Narrative Exposure Therapy as recommended by NICE. The difference is that we deploy such therapies within an established therapeutic relationship as part of this rehabilitation programme, rather than as stand-alone therapies and over a longer period: the average length of treatment at Freedom from Torture is two and a half years.	including a broad range of psychological interventions where there is available evidence.
33.	SH	Freedom From Torture	General	General	We share Dr Joanne Stubley and Dr Maria Eyres' concerns in relation to the absence of psychodynamic / psychoanalytic / relational modalities in the UK Psychological Trauma Society's draft Guideline for the treatment and planning of services for complex post-traumatic stress disorder. We agree that second phase "trauma focused treatments" that have an evidence base	Thank you for your comment. We will endeavour to address your concern that continuity of care and flexibility of care is important for people with complex PTSD where there is available evidence.

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					<p>for PTSD cannot simply be transposed on to complex PTSD. As they explain:</p> <p>Although there is some evidence for a phase based approach in using TF-CBT or EMDR, there is less evidence for other modalities and some studies suggesting the overall evidence remains unclear. (De Jongh et al 2016). In suggesting this is how services should be commissioned, there is a risk of fragmenting the care of these patients. Thus they may obtain phase one approaches from one clinician or service before moving to a different one for the active trauma work. They may then need to move yet to another service for the third phase. Engagement requires a relationship and drop-out rates will inevitably increase if these movements between phases occur. The use of phase based approaches in severe dissociative disorders has demonstrated both, the importance of the therapeutic relationship through all the phases, and the need to work flexibility with this notion so that patients may</p>	<p>We will consider all available high quality evidence on how to optimise treatment for people with PTSD, including phased approaches to treatment and a broad range of psychological interventions where there is available evidence.</p>

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					move back and forth between different needs and different issues and the phases may not be linear. <sup>18</sup>	
34.	SH	Freedom From Torture	General	General	<p><u>Clients have also stressed the importance of trust and continuity with their therapist “I would have found it very very difficult to move clinician if I hadn't had the chance to already build trust with them”.</u></p> <p>The evidence in the current Guidelines is based on research using participants who are mostly not torture victims. It is well documented that torture survivors in host states present research challenges; they come from diverse cultural and linguistic backgrounds, may experience multiple trauma, or previous mental health conditions, which can be complicated by the length of time that has passed since the trauma and the difficulty in conducting controlled studies.<sup>19</sup> However, the success of rehabilitative efforts can be assessed by reference to</p>	Thank you for your comment. There may be limited evidence in torture survivors but we will carefully review such evidence and determine where possible what the most effective interventions are for victims of torture.

<sup>18</sup> Drs Joanne Stubley and Maria Eyres (June 2016), Co-Chairs for Historical Childhood Sexual Abuse Task Group, Executive Committee of Faculty of Medical Psychotherapy, Royal College of Psychiatrists, *Initial Response to the Document: Guideline for the treatment and planning of services for complex post-traumatic stress disorder (CPTS)*

<sup>19</sup> Mary R. Fabri, Psy.D (2011) Torture Volume 21, Number 1, *Best, promising and emerging practices in the treatment of trauma: What can we apply in our work with torture survivors*

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					the quality of life of the patients, as indicated by the patients themselves. <sup>20</sup> Recently, we have developed a comprehensive service user engagement programme to give survivors more of a voice in the running and direction of the organisation, an essential element in rehabilitation and the task of developing a sense of agency. Outcome data from the Measure of Change & Outcome (MOCCO), the tool developed by Freedom from Torture to track the progress of survivors of torture through therapy (Freedom from Torture 2014) shows a statistically significant correlation between improvements in the clients' external world and improvements in their psychological state. <sup>21</sup>	
35.	SH	Freedom From Torture	General	General	It is our experience that many clients benefit psychologically from activity-based and social groups. Clients often tell us about the progress they feel they have made as a result of group work. <u>One client explained "Different approaches meet different needs. My psychologist left the organisation. I had the choice to wait a few months to see another one or to start group work. I</u>	Thank you for your comment. We will consider all available high quality evidence on how to optimise treatment for people with PTSD, including phased approaches to treatment and a broad range of psychological interventions

<sup>20</sup> Fuhrer (2000) (as cited in The Medical Foundation for the Care of Victims of Torture (2010), [A Remedy for Torture Survivors in International Law: Interpreting Rehabilitation](#))

<sup>21</sup> Freedom from Torture (2016) *Audit of prevalence of torture among patients of a North London Trauma Clinic*. Unpublished

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					<p><u>went to the group. It helped me to move on but to start it was very difficult. To start with I just went and didn't say anything. I just listened but the group taught me that I was not the only one that had gone through my experience. Slowly I started to open up</u>.</p> <p>Clients have also spoken of the sense of belonging at FFT, especially when they visit the centre for communal activities. For example, clients have told us that they relax as soon as they push the doorbell at our centres, or receive an appointment letter from FFT. <u>One client explained "FFT builds hope in our hearts. When you have people that care for you it gives you hope. You can open up. Most of us need to build up that hope."</u></p> <p><u>Another service user considers that "it's helpful meeting people who've been through the same experience. It gives you a sense of hope and interest. For example, I joined the chess club. Pleasure is contagious. If you see other people laughing you laugh even if you don't know why.</u></p>	where there is available evidence.
36.	SH	Freedom From Torture	General	General	As well as specifying the importance of group work for survivors of torture, the Guidelines should address survivors' isolation and the need for other agencies to get clients involved in purposeful activities. <u>As one survivor put it "being directed just to 1 organisation doesn't help. You are only at that organisation for 1</u>	Thank you for your comment. We will consider factors such as practical support and case coordination which will address the issue of social support

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					<p><u>hour a week. What do you do for the rest of the time?"</u></p> <p>Our clinical experience and survivor testimony suggests that longer therapies are more effective for complex problems. It should also be noted that research into the mental health of Cambodians two decades after they had resettled in the United States found that this population continues to have high rates of psychiatric disorders associated with trauma.<sup>22</sup> A 10 year treatment outcome study into Cambodian refugees in the United States with posttraumatic stress disorder who had been in continuous treatment for 10 or more years found that thirteen patients were judged to have good outcomes, and 10 had relatively poor outcomes 'even with comprehensive continuous treatment over a period of 10 or more years, a substantial minority was still impaired'.<sup>23</sup></p>	
37.	SH	Freedom From Torture	General	General	<p><u>At a roundtable preparing from this submission one of our service users implored us to "give a voice to people that have</u></p>	Thank you for your comment. We will have service users as part of our

<sup>22</sup> Grant et al (2005), JAMA August 3, 2005—Vol 294, No. 5 579, *Mental Health of Cambodian Refugees 2 Decades After Resettlement in the United States*

<sup>23</sup> James K. Boehnlein, MD, MSc,\*† J. David Kinzie, MD,\* Utako Sekiya, MD,\* Crystal Riley, MA,\* Kanya Pou,\* and Bethany Rosborough, BS\* (2004) (The Journal of Nervous and Mental Disease Volume 192, Number 10, October 2004), *A Ten-Year Treatment Outcome Study of Traumatized Cambodian Refugees* Volume 192, Number 10, October 2004

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					<i>survived</i> ". We strongly recommend NICE consider evidence from survivors of torture on treatment modalities that have yielded positive results as well as clinical experience, which alongside research constitute evidence based practice. <sup>24</sup>	guideline committee. Their input is invaluable in shaping the recommendations for this guideline.
38.	SH	Freedom From Torture	General	General  2005 Guideline , sections: 10.5	<ul style="list-style-type: none"> <li>▪ A denial of appropriate treatment for survivors of torture risks re-traumatisation</li> </ul> <p>As section 10.5 correctly identifies, securing refugee or other immigration status may take several years. This is also the experience of our specific client group, despite many of whom having medical evidence of their torture. As the previous section detailed, uncertainty for a torture survivor about whether he or she will be returned to the state where torture was experienced can cause or exacerbate pre-existing psychological health problems and this means that access to rehabilitation services whilst the outcome of an asylum claim is awaited is imperative. During this period, survivors frequently experience intrusive memories and distress, symptoms may increase and coping mechanisms such as avoidance may be impaired leading to a deterioration of mental health.</p>	Thank you for your comment. We will consider this information when reviewing the evidence and developing our recommendations.

<sup>24</sup> Drs Joanne Stubley and Maria Eyres (June 2016), Co-Chairs for Historical Childhood Sexual Abuse Task Group, Executive Committee of Faculty of Medical Psychotherapy, Royal College of Psychiatrists, *Initial Response to the Document: Guideline for the treatment and planning of services for complex post-traumatic stress disorder (CPTS)*

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39.	SH	Freedom From Torture	General	General	Exclusion from therapeutic treatment during asylum applications raises a profound ethical question for therapists when torture survivors have presented with extreme levels of distress. By denying treatment the service is, in effect, condemning the person to many years of distress and pain. Not only does withholding therapeutic treatment on the basis of their immigration status risk re-traumatisation, but so might service providers who don't know how to do appropriate work with survivors of torture, or who don't allow for stabilizing. Related to this, it is also our experience that survivors who are granted refugee status or some other form of permission to remain in the UK may experience profound disappointment that their psychological difficulties persist despite this positive change to their legal status. Often the grant of protection is accompanied by grief and the challenge of re-building both their psychological and physical health and a new life in exile. Some survivors actually experience a worsening of symptoms and a deterioration in mental health during this transitional phase requiring additional clinical and non-clinical care and support. Only once this transitional phase is passed, can rehabilitation enter a new phase in which the underlying causes of trauma may be addressed.	Thank you for your comment. We will consider this information when reviewing the evidence and developing our recommendations, in particular those concerned with improving access to treatment
40.	SH	Freedom From	GENERA	General		Thank you for highlighting that not

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		Torture	L		<ul style="list-style-type: none"> <li>A denial of appropriate treatment for survivors of torture is costly to the NHS and social services</li> </ul> <p>It is important to recognise that the complexity of torture survivors' needs is such that multiple specialist and mainstream agencies are often required if the totality of a survivor's health needs are to be met. For example, Freedom from Torture does not provide hospital or full primary care services, however by working with public healthcare providers we can help ensure that survivors' health problems are correctly diagnosed and appropriate services are delivered. It is our experience that the lack of experience and understanding of working with torture survivors within mainstream services can lead to misdiagnosis and inappropriate procedures such as expensive scans and repeated referrals made to the wrong types of specialist. The withholding of treatment whilst a possibly lengthy asylum application is being processed means that a person's mental state is likely to deteriorate further, making their condition much more difficult to treat when and if a service ever does engage.</p>	<p>accessing care is a concern for treating people with PTSD.</p> <p>This may addressed when we review the question: "For adults, children and young people with clinically relevant post-traumatic stress symptoms, what factors should be taken into account in order to provide optimal care and access to care across all conditions and coordination of care?"</p>
41.	SH	Freedom From Torture	General	General	<p>Provision of specialist services from the outset are likely to be efficient and cost-saving in the long term. The NHS and social services incur a number of hidden costs as a result of a delay or failure to diagnose and appropriately treat PTSD in torture survivors:</p>	<p>Thank you for your comment. The Guideline Committee will consider the cost effectiveness of interventions and services for PTSD when making recommendations. Prioritisation of guideline review questions for</p>

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					<ul style="list-style-type: none"> <li>○ Misdiagnosis leading to ineffective and expensive inappropriate treatment</li> <li>○ Overuse of medication</li> <li>○ Inappropriate referrals</li> <li>○ Use of multiple agencies</li> <li>○ Drop out from (inappropriate) services</li> <li>○ Excessive use of acute care, A&amp;E units</li> </ul> <p>It is more cost effective for front line services to adequately meet needs of torture survivors as opposed to them being forced to use A&amp;E or receive psychiatric admissions when their symptoms escalate, or referred to multi agencies who are unable to meet their needs. For example, it was estimated in 2014 that the average GP appointment costs the NHS £25, whereas the average A&amp;E appointment costs between £59 and £117.<sup>25</sup> The Department of Health calculated that the average cost to the NHS for any visit to A&amp;E, whether it results in an admission or discharge was £124 in 2013 and £132 in 2014.<sup>26</sup></p>	economic analysis will take into account the anticipated magnitude of resource implications arising from potential recommendations.

<sup>25</sup> Nursing Times (13 March 2014), [Should patients be charged for £10 for non-urgent A&E treatment?](#)

<sup>26</sup> Department of Health (November 2015), [Reference costs 2014-15](#) also see Nuffield Trust (March 2015) Policy Briefing #3, [What's behind the A&E 'crisis'?](#)

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					There also needs to be a recognition that if systemic family assessments are not undertaken, there will be a long term impact on wider family and subsequent generations, and thus a resulting higher costs to the NHS and social services.	
42.	SH	Freedom From Torture	General	General	<p>Recommendations</p> <p>In light of the foregoing we recommend that:</p> <ol style="list-style-type: none"> <li>1. The unique experiences, symptoms, and needs of survivors of torture and other complex trauma should be specifically addressed in the new NICE Guidelines</li> <li>2. Survivors of torture should not be conflated with asylum seekers and refugees, but we hope that the section on working with these groups is clarified to ensure no survivor in need of assistance is turned away because of their immigration status</li> <li>3. The Guidelines should give clear guidance on the treatment of Complex PTSD and Enduring Personality Change, given the impact of both these conditions on survivors of torture and the recognition of these in the upcoming edition of the International Classification of Diseases</li> </ol>	<p>Thank you for your comment. Please see comments for each of your points raised.</p> <p>1 and 4: The needs of torture survivors will be addressed where the evidence allows us to make recommendations. Where evidence for the interventions that you mention is available</p> <p>2: We agree with your point and will take this into consideration when developing recommendations</p> <p>3: The treatment of complex trauma will be included in the</p>

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					<p>4. Appropriate treatment for survivors of torture should be recommended in the new NICE Guidelines, taking into account survivors' testimony and specialised clinical experience as well as research evidence. This includes the recognition that:</p> <ul style="list-style-type: none"> <li>a. A holistic, integrated approach based on the Three Phase Model usually requires services delivered by a multi-disciplinary team</li> <li>b. Communal activities augment therapies</li> <li>c. Long-term therapy and support must be available for those requiring it</li> <li>d. Children and young people (both those who have been separated from their families and those who remain with their families, whether in exile or not) have specialist needs requiring specialist multi-disciplinary service development and provision.</li> </ul> <p>5. There is a need for specialist training and supervision by torture rehabilitation experts</p>	<p>guideline where there is available evidence and where possible enduring personality change.</p> <p>5: Any additional training will need to be considered at a local level.</p>
43.	SH	The Yoga Clinic	General		PTSD and Complex PTSD are not used consistently. If the Scope is to include Complex PTSD, for every mention of PTSD	Thank you for your comment. We will consider complex PTSD where

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					<p>there should also be included 'Complex PTSD'.</p> <p>If the intention is to <i>not</i> refer to Complex PTSD in some sections, this should be explicitly mentioned.</p> <p>Distinctions should be made between Developmental Trauma, Complex PTSD and PTSD. This is especially relevant when looking to provide guidelines for folks that have experience inter-relational abuse and/or neglect during the developmental stages 0-2yrs.</p>	<p>evidence is available. We do not agree however that the terms should be used simultaneously throughout the scope as if no evidence is available, and in the absence of an agreed definition, we are concerned that we would be unable to provide recommendations that would improve care for these individuals and may in fact result in harm.</p> <p>We will not be considering "developmental trauma" arising in 0-2 year olds as distinct from PTSD as this would be outside the remit provided by the Department of Health. Where there is evidence available for 0-2 year old children with, or at risk of developing, PTSD it will be considered.</p>
44.	SH	The Yoga Clinic	General		Where 'Complex PTSD' is used, it should be defined.	Thank you for your comment. Complex PTSD will be defined during the development of the guideline.
45.	SH	The Tuke centre	General	General	Treatment pathway - The pathway should include a separate subheading for complex trauma within the interventions arm.	Thank you for your comment. The treatment pathway will be updated

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					Within the organisation arm reference should be made to training and supervision of staff, appropriate settings for different cases and experience of staff to treat the different cases.	when the revised guideline is published.
46.	SH	Freedom From Torture	general	2005 Guideline , sections:  2.1.1 2.2.3 10.5 10.6	<ul style="list-style-type: none"> <li>▪ The unique experiences of survivors of torture and other complex trauma are omitted from the NICE Guidelines on PTSD;</li> </ul> <p>Survivors of torture are mentioned in several sections of the 2005 Guidelines, albeit briefly, which recognise that: survivors of torture are at risk of PTSD; that research has shown high PTSD rates for survivors of torture; that by virtue of experiences such as torture, refugees and asylum seekers are more likely to experience PTSD than the general population; and that various traumatised groups including survivors of torture have particular needs which the charitable sector has responded to.</p> <p>However, it is our contention that the unique experiences of survivors of torture and resulting appropriate treatment have not been adequately captured in the Guidelines. This is despite a sizeable number of torture survivors arriving in the UK each year. There were 32,414 applications for asylum in the UK in 2015.<sup>27</sup> Estimates of the prevalence of torture survivors among</p>	Thank you for your comment. The needs of torture survivors will be addressed where the evidence allows us to make recommendations and so revise the guideline. We will also include the experience and expertise of GC members, including service users, to help inform any recommendations for survivors of torture and other complex trauma.

<sup>27</sup> Refugee Council (May 2016), [Asylum statistics Annual Trends](#)

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					refugee populations vary widely. <sup>28</sup> A recent appraisal of the research literature reporting prevalence of torture and/or war-related potentially traumatic experiences (PTEs) in adult forced migrants living in high-income countries which examined 41 articles fulfilling the inclusion criteria, with a total number of study participants of 12,020 (median 170) found that "Reported prevalence rates of torture ranged between one and 76 % (median 27 %). Almost all participants across all studies had experienced some kind of war-related PTE". <sup>29</sup> Assuming a conservative estimate that ten percent of asylum applicants have been tortured, that would mean an additional 3,200 survivors of torture coming in to the UK each year currently. In addition, 4,000 Syrians will arrive in the country each year for the next five years through the Syrian Resettlement Programme and the government has announced that torture is one of the vulnerability criteria used to select people for the programme. This in addition to those who have already in the UK claiming	

<sup>28</sup> Kalt A et al. 2012. Asylum Seekers, Violence and Health: A Systematic Review of Research in High-Income Host Countries. In American Journal of Public Health: March 2013, Vol. 103, No. 3, pp. e30-e42.

Mills, E. 2005. Prevalence of mental disorders and torture among Tibetan refugees: A systematic review. In BMC International Health and Human RightsBMC series - open, inclusive and trusted. 55:7

<sup>29</sup> Erika Sigvardsdotter, Marjan Vaez, Ann-Marie Rydholm Hedman, Fredrik Saboonchi (2016), Journal on Rehabilitation of Torture Victims and Prevention of Torture Volume 26, Nr. 2, [Prevalence of torture and other war-related traumatic events in forced migrants: A systematic review](#)

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					asylum or settling after being granted refugee status. The majority of these survivors will have high levels of trauma and complex social and legal needs, to which mental health professionals will need to respond.	
47.	SH	Freedom From Torture	General	2005 Guideline , sections: 2.1.1 2.2.3 10.5 10.6	<p>Section 10.5 'Working with refugees and asylum seekers' of the current Guidelines provides a useful starting point, noting the complexities of the social circumstances of this group, their levels of trauma and issues around working across cultures. However, we contend that survivors of torture should be specifically addressed in the NICE Guidelines on PTSD as there are certain characteristics of survivors of torture which set them apart from asylum seekers and refugees and which we believe, warrant specific attention.</p> <p>Whilst it is likely, given the nature of their experiences, that survivors of torture have a fear of persecution if returned to their home country and therefore most will have made an application for asylum or other form of leave, or have been awarded refugee status in the UK, not all will have done so. Indeed, although many asylum seekers and refugees will have been traumatised through exposure to violence and other stressors, not all asylum seekers/refugees will have experienced torture.</p>	Thank you for your comment. Where the evidence allows and based on the guideline committee's views, including service users, we will address the needs of survivors of torture
48.	SH	Freedom From Torture	general	2005 Guideline	The Guidelines should also recognise that in some circumstances it is necessary in therapeutic terms to view the	Thank you for your comment. Where the evidence allows and based on the

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				, section: 10.5	<p>family, as a whole, as a 'victim of torture'. Frequently, multiple members of a family have experienced torture either directly or indirectly (for example where children are present during the rape of a parent). It may be very difficult for some members of a family to disclose their experiences (for example a father who feels unable to disclose that he was raped) and disclosure, particularly for young girls and boys, may take a very long time especially if there is a strong sense (including for children) that there is a need to protect other members of the family. In these complex cases a holistic assessment should address the needs of the family as a whole with careful consideration given to each individual family member as well as to subgroups including the parents as a couple and children as siblings, with services delivered accordingly.</p> <p>Section 10.5 states that the expression of emotional disturbance may be modified "beliefs of the sufferer concerning health services", which we believe should be further explained. Survivors of torture may view the NHS as agents of the state and thus intertwined with (potentially negative) experiences during the refugee status determination process, or that UK government officials are working in collaboration with state officials from their country of origin. <u>For example, one survivor explained, "There is a fear of return but also a fear of being captured in the UK by the people that tortured you- you think the Home Office is working with them."</u></p>	guideline committee's views, including service users, we will address the needs of survivors of torture and their families including children.

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49.	SH	Freedom From Torture	General	2005 Guideline , sections: 2.1 2.1.1 2.3.6.1	<u>Complex PTSD and enduring personality change</u> Whilst the current NICE Guidelines recognise that 'Disorders of extreme distress not otherwise specified/complex PTSD' may develop after extreme prolonged or repeated trauma such as torture and that 'many PTSD sufferers will have at least some features' of 'enduring personality changes after catastrophic experience' which needs to be taken into account when treating PTSD sufferers, it states that the Guideline does not apply people for whom this is their main diagnosis.	Thank you for your comment. We will consider the wording regarding whom this guideline is relevant for in the update and review relevant evidence.
50.	SH	Freedom From Torture	General	2005 Guideline , sections: 10.5 6.10.1.3	We note that section 10.5 states that interventions in phase one are likely to involve medication. We recommend the Guidelines explain that this is despite the fact that research evidence for medication is low and recent meta-analysis have confirmed that limited effectiveness of medication. <sup>30</sup> The sedative effect may have short term benefits, however cognitive effects may delay long term recovery. There is also the impact that clients may see medication as the answer to their problems and so may not engage in more appropriate talking therapy which addresses the	Thank you for your comment. We will be conducting an updated review on the effectiveness of pharmacological treatments for those with PTSD.

<sup>30</sup> Hoskins et al (2015), *Pharmacotherapy for post-traumatic stress disorder: systematic review and meta-analysis*. In *The British Journal of Psychiatry* (2015) 206, 93-100.

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					real problems. Our clinical experience suggests that in the NHS torture survivors may be offered medication more readily than other groups because the barriers to psychological therapies are greater. Furthermore, the Guidelines appear to apply different standards to recommendations around medication to those around psychological therapies. For example, paragraph 6.10.1.3. of the current Guidelines suggest that paroxetine should be offered even though there is no evidence of clinical benefit and there is no recommendation that people should be told there is no evidence.	
51.	SH	BeTr Foundation	1	12-13	<p>This is everyone. A statement that directs the Guideline to those who work in the field on behalf of sufferers would be helpful. The Guideline is for those unaffected by PTSD to follow, not those affected by it.</p> <p>Line 12 refers to 'complex PTSD'. This demands a definition, given that the term has been around for around 25 years (Herman, 1990; 1992) and is still debated even though it is a well-used term in the clinical and research field.</p>	<p>Thank you for this comment we provide guidance in the guideline detailing who this guidance is intended for along with a separate publication for the public</p> <p>We will be defining complex PTSD during the early development of the guideline.</p>
52.	SH	First Person Plural	1	6	The surveillance review decision mentioned in this line has excluded the Recognition section of the guidelines from this review, yet it doesn't appear to have considered the differential diagnosis of PTSD from complex trauma-related dissociative disorders i.e. dissociative identity disorder and similar. We feel	Thank you for your comment. The guideline will not be covering the diagnosis of PTSD. The NICE surveillance report concluded that the introduction of DSM-V for adults is

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					this is a significant omission as these complex dissociative disorders are not routinely screened for, but people suffering them may also meet diagnostic criteria/symptom profiles for PTSD as defined by screening tools for PTSD and both DSMV and ICD10. It is important that this co-morbidity is screened for because someone with dissociative identity disorder who receives treatment only for their PTSD symptoms is unlikely to benefit from this treatment and may indeed be damaged by it.	unlikely to have an effect on the current diagnostic recommendations. And that that there is currently a lack of data on validated screening tools. Whilst they acknowledged the impending release of ICD-11 will be significant, it is not due to be published until 2017/early 2018.
53.	SH	Association for the Advancement of Meridian Energy Techniques	1	6	<u>Surveillance review decision document:</u> We are concerned that this document does not include references to the research into Emotional Freedom Techniques (EFT), acupoint stimulation or other energy psychology techniques for PTSD. There is only one reference included (Zhang Y, Feng B et al 2011) to a paper concerning acupoint stimulation as an adjunct to CBT but this paper has very poor methodology as it conflates the 3 groups it claims to separate (control, CBT and acupoint stimulation). Papers with better methodology and papers on EFT as standalone trauma-focussed psychological therapy have not been mentioned, but some are referenced here. An example would be Karatzias et al (2011). AAMET brought this paper to the attention of NICE during the 2011 consultation as to whether there should be a review of the PTSD guideline and the NICE response was (from memory – words to the effect) that it showed promise/was of interest but insufficient evidence of itself at that point to warrant guideline review - so it would be	Thank you for your comment. We will be doing a new comprehensive search for treatment of PTSD and will also consider the references you have provided if they meet our criteria for inclusion.  Please note that NICE does not accept unsolicited submissions of evidence from stakeholders. Instead, evidence is identified through a systematic search according to a protocol agreed by the Guideline Committee.

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					considered at a future review point. However this commitment would appear to have been neglected within the current review decision and scoping materials. There have been additional research papers suggesting efficacy for the use of EFT for PTSD since 2011. Some will be referred to within these comments. However there have been communication failures meaning that AAMET became aware of the existence of the current review process and the draft scope consultation only very late in the consultation period and one board member alone had only 36 hours to prepare these comments when they should have been prepared by our team of research experts in collaboration with our US colleague organisation, Association for Comprehensive Energy Psychology (ACEP). We will do our best job within limited time of including relevant citations here but inevitably some may get missed. We therefore request to submit separately as soon as is possible a full list of relevant peer-reviewed research papers into EFT for PTSD together with brief extracts that can inform the Guidance Development Team accurately of the extent of the evidence base for EFT for PTSD.	
54.	sh	Association for the Advancement of Meridian Energy Techniques	1	6 (Surveillance review)	With reference to PTSD Surveillance review decision document page 63 of 80, Research Recommendations RR26-02: "Adequately powered effectiveness trials of trauma-focused psychological interventions for the treatment of PTSD (TF-CBT	Thank you for your comment. We will be doing a new comprehensive search for treatment of PTSD and will review the references you have provided if

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				decision document )	<p>and EMDR) should be conducted.”</p> <p>It would be helpful if this could specify EFT in addition to TF-CBT and EMDR. In the separate research summary mentioned in the previous paragraph we will show that existing evidence makes a case for this further research. The citations hurriedly included below can be considered in the interim until the better-prepared information can be submitted.</p> <p>Review in Journal of the American Medical Association: Psychotherapy for Military-Related PTSD A Review of Randomized Clinical Trials Maria M. Steenkamp, PhD; Brett T. Litz, PhD; CharlesW. Hoge, MD; Charles R. Marmar,MD . JAMA. 2015;314(5):489-500. doi:10.1001/jama.2015.8370</p> <p>“In military and veteran populations, trials of the first-line trauma-focused interventions CPT and prolonged exposure have shown clinically meaningful improvements for many patients with PTSD. However, nonresponse rates have been high, many patients continue to have symptoms, and trauma-focused interventions show marginally superior results compared with active control conditions. There is a need for improvement in existing PTSD treatments and for development and testing of novel evidence-based treatments “ (such as EFT, it is mentioned in this review)</p> <p>Karatzias, T., Power, K., Brown, K., McGoldrick, T., Begum, M., Young,J., . . . Adams, S. (2011). A controlled comparison of the</p>	they meet our criteria for inclusion.

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					<p>effectiveness and efficiency of two psychological therapies for posttraumatic stress disorder: Eye Movement Desensitization and Reprocessing vs. Emotional Freedom Techniques. Journal of Nervous and Mental Disease, 199, 372–378. doi:10.1097/NMD.0b013e31821cd262</p> <p>“Overall, the results indicated that both interventions produced significant therapeutic gains at posttreatment and follow-up in an equal number of sessions. Similar treatment effect sizes were observed in both treatment groups. Regarding clinical significant changes, a slightly higher proportion of patients in the EMDR group produced substantial clinical changes compared with the EFT group.”</p> <p>Feinstein, D. (2012). Acupoint stimulation in treating psychological disorders: Evidence of efficacy. Review of General Psychology, 16, 364-380. doi:10.1037/a0028602... Available at: <a href="https://innersource.net/ep/images/stories/downloads/Acupoint_Stimulation_Research_Review.pdf">https://innersource.net/ep/images/stories/downloads/Acupoint_Stimulation_Research_Review.pdf</a></p> <p>This is a review paper that showed that EFT met American Psychological Association (APA) criteria for “probably efficacious” therapy. Since publication (2012) later and other papers now provide sufficient evidence for EFT to meet APA criteria as “efficacious therapy” and APA allow continuous professional development credits for certain EFT and EP courses run by ACEP. Feinstein’s review considered 18 fully</p>	

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					<p>randomised controlled trials.                      "The 18 RCTs all meet established significance thresholds and showed strong effects in the 16 studies where effect size was calculated".                      These 18 RCTs covered a range of anxiety-based conditions.                      "Four RCTs and five outcome studies that did not use a comparison group provide evidence on the efficacy of brief acupoint-assisted therapy in treating PTSD." (EFT is an acupoint-assisted therapy)</p>	
55.	SH	Helen Bamber Foundation	1	11	The target audience ('who the guideline is for' should specifically include NGOs involved in the assessment and treatment of people with PTSD	Thank you for your comment. NICE guidance is primarily for NHS commissioned services, though others services may choose to adopt it.
56.	SH	British Association for Psychopharmacology	1	12	The terminology 'complex PTSD' is first used here and then repeatedly employed throughout the document. It would be essential to clarify what is meant by this term, which is not a widely accepted diagnosis. It is often applied to patients with histories of aversive experiences in childhood, features of certain personality disorders, and symptoms similar to PTSD: but attempts should be made to delineate this condition and to distinguish it from the diagnosis of PTSD which has been used in the various psychological and pharmacological treatment studies.	Thank you for your comment. During the development of the guideline we will generate a working definition of complex PTSD with the guideline committee.
57.	SH	First Person Plural	1	12	The draft scope includes people who have complex PTSD. This is an additional group of people not specifically excluded from	Thank you for your comment. We are including complex PTSD in the update

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			2	46	the original 2005 guideline. We strongly feel this group should not be included as a parenthesised aside but identified as a separate group within the guideline development process, particularly in light of the debates in which complex PTSD is considered to be more accurately defined as a dissociative, rather than an anxiety disorder. Complex PTSD needs specific recommendations that are derived only from evidence from research which focuses specifically on those suffering complex PTSD and not from evidence focused on single traumatic event PTSD sufferers or mixed complex and single traumatic event PTSD sufferers.	of this guideline where there is available evidence. However, we will not be using the terms simultaneously throughout the scope.
58.	SH	The Intensive Care Society	1	16	Instead of “clinical psychologists”, interested professional groups should include “practitioner psychologists” – a term that includes HCPC-registered health and counselling psychologists as well as clinical psychologists. All three groups may be involved in providing care for people with PTSD.	Thank you for your comment. The list is indicative not exclusive and our recommendations will encompass the work of a range of applied psychologists
59.	SH	East London NHS Foundation Trust	1	19	Psychological Wellbeing Practitioners within IAPT are not included in this list. We think they should be included as they will often be providing initial screenings for people with PTSD.	Thank you for your comment. The list is indicative not exclusive and our recommendations will encompass the work of a range of applied practitioners
60.	SH	The Yoga Clinic	2	36 - 41	Although sexual orientation is included, no mention is made of gender identity, specifically non gender conforming identities (incidentally your equal opps. monitoring form only included male/female)	Thank you for your comment. We have added gender identity to the EIA form. The equal opportunities form is not specific to PTSD. Section 1.1 is.

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61.	SH	BeTr Foundation	2	38-41	The guideline committee has an obligation not just to be sensitive to, but to learn from other cultures, given that PTSD is proving so difficult to resolve. Having only two 'talking therapies' and drugs as the treatment recommendations since 2005 and no narrative of 'cure' tells us we have work to do and that the current way-of-thinking around trauma needs to change. If we have something more to learn then other cultures might allow us the insight needed to be much more effective than we are. Being 'sensitive' is another way of admitting to a lack of knowledge.	Thank you for your comment. If there is any culturally relevant/specific treatments that have been studied in high quality trials we will consider these in the recommendations.
62.	SH	First Person Plural	2	49-51	Once again, we strongly feel that there should be a specified exclusion of people who suffer dissociative identity disorders and similar trauma-related dissociative disorders comorbid with (or misdiagnosed as) PTSD from the scope of the guidelines. This was partially specified in the Section 2 of the original 2005 full guidelines and at the very least the exclusion should be retained at the level of 'dissociative disorders' but we feel that more specificity is needed (i.e. by referencing to dissociative identity disorder [DSMv 300.14; ICD10 F44.81] in particular because this group of people are likely to be erroneously treated under the PTSD guidelines if not specifically excluded. To ensure this we suggest the scope includes a section titled "Groups that will not be covered" which contains those who meet diagnostic criteria for Dissociative Identity Disorder; DID-like Other Specified Dissociative Disorder; Complex PTSD (or the related DSMV/ICD10 conditions) and other trauma-related	Thank you for your comment. We acknowledge your point that people with PTSD may be misdiagnosed with dissociative identity disorders. Whilst we are not reviewing the diagnosis of PTSD, we will look at the impact of dissociative symptoms in the review question that looks at how to treat PTSD in the presence of comorbidity.

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					conditions which are not one traumatic incident PTSD.	
63.	SH	East London NHS Foundation Trust	2	45-46	The original draft scope included specific groups such as torture survivors. These are no longer specified. We wanted to check that specific groups such as refugees and asylum seekers (including survivors of torture), survivors of repeated childhood trauma (including childhood sexual or physical abuse), survivors of repeated trauma in adulthood and veterans would be included under this umbrella term.	Thank you for your comment. We will be considering all of the populations you described where there is evidence.
64.	SH	Helen Bamber Foundation	2	31	Under 'equality considerations' the relevant client groups should include undocumented migrants who have limited but significant entitlements to NHS care in England	Thank you for your comment. We have added undocumented migrants to the EIA form.
65.	SH	Association for the Advancement of Meridian Energy Techniques	2	32	Equality considerations. We are in contact with numerous relief workers who have used EFT for PTSD worldwide in disaster zones, areas that have suffered genocide etc. It has been possible to adapt it to overcome language barriers. It has been possible to train local helpers. Help has been possible working with groups, sometimes large groups and in very few sessions. There are papers but not available to the writer at short notice, details to follow. Quoted in Feinstein 2012 review is a paper by Johnson et al, although Johnson used Thought Field Therapy (TFT) the forerunner to EFT. Johnson, C., Shala, M., Sejdijaj, X., Odell, R., & Dabishevci, D. (2001). Thought Field Therapy: Soothing the bad moments of Kosovo. Journal of Clinical Psychology, 57, 1237–1240. doi:10.1002/jclp.1090	Thank you for your comment. We will consider all high quality evidence for the treatment of PTSD and will review the references you have provided if they meet our criteria for inclusion.

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					<p>“Carl Johnson—a retired Department of Veterans Affairs (V.A.) psychologist and a diplomate of the American Board of professional Psychology—based on his postretirement work with people who had been severely traumatized. Johnson learned of acupoint tapping toward the end of his career with the V.A. After retiring, he began bringing the approach to parts of the world that had sustained widespread disasters such as genocide or warfare impacting civilian populations. Using TFT, the treatment focused on reducing severe emotional reactions evoked by specific traumatic memories, which often involved torture, rape, and witnessing loved ones being murdered. Johnson’s initial report described his work with 105 people during his first five visits to Kosovo following the genocide, claiming strong improvement with 103 of them (Johnson et al., 2001).”</p> <p>We would like to suggest that inclusion of EFT will improve access to PTSD treatment for groups such as refugees.</p>	
66.	SH	First Person Plural	2	38	<p>The inclusion of people with co-morbidities in relation to inequalities is welcome. However, we feel that if the co-morbidities considered do not specifically exclude dissociative identity disorders and similar complex trauma-related</p>	<p>Thank you for your comment. We acknowledge your point that people with PTSD may be misdiagnosed with dissociative identity disorders and that</p>

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					dissociative conditions from the scope, the guideline will have an equality impact on this group by potentially drawing them into PTSD treatments which may at best be ineffective for them and at worst damaging.	they may not get the appropriate treatment.  To help address this, in the comorbidities question we will look at the impact of dissociative symptoms on the treatment of PTSD.
67.	SH	The Intensive Care Society	2	45	Note that people at risk of or with PTSD include critical care patients and former patients. There is a body of research showing a high prevalence of PTSD (up to about 30%) among this group of patients. Hospital critical care follow-up services are frequently attended by patients with PTSD, but there is a dearth of services to which patients can be referred. Former critical care patients often describe PTSD flashbacks of hallucinations and delusions (a common experience in intensive care units) rather than intrusive memories of real events. These symptoms may be misunderstood by GPs, and patients may be referred to inappropriate services. Many critical care patients have symptoms of PTSD for years, but are never diagnosed or referred for relevant treatment.	Thank you for your comment. We will not be reviewing the identification of people with PTSD in this guideline. However, we will be looking at the following question: For adults, children and young people with clinically relevant post-traumatic stress symptoms, what factors should be taken into account in order to provide optimal care and access to care across all conditions and coordination of care?
68.	SH	The Tuke centre	2	49	The draft scope fails to mention common comorbid conditions common in complex presentations such as dissociative disorders which if present have a considerable impact on treatment approaches. These were noted in the meeting notes	Thank you for your comment. To help address this, in the comorbidities question we will look at the impact of dissociative symptoms on the treatment

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					but then don't appear in the scoping document. We feel it is very important that these are directly referenced.	of PTSD.
69.	SH	East London NHS Foundation Trust	2	51	People with physical health conditions or chronic pain are not currently included under co-existing conditions in the draft scope. People with PTSD commonly have physical health conditions and/or chronic pain either related to injuries from the original trauma or as manifestations of trauma symptoms. We therefore feel that this class of co-existing conditions should be specifically included.	Thank you for your comment. We will not be explicitly looking at pain as a co-existing condition. Rather we will be referring people to the relevant NICE guidelines.
70.	SH	BeTr Foundation	3	65-69	Pharmacological interventions all carry side-effects, some common, some very common (according to NHS and BBC health websites) and all seemingly unpleasant and unwanted. Side effects are likely to confound the patient, the practitioner and the researcher and should be published in the Guidelines where medication is justified to inform and refine treatment decisions.	Thank you for your comment. We will consider the harms as well as the benefits of any treatment in all of our reviews.
71.	SH	East London NHS Foundation Trust	3	54-55	Voluntary sector organisations and private providers are not currently included in "settings". We have received feedback that services provided by these providers (who may be commissioned to provide services following disasters or terrorist incidents) may not always adhere to NICE recommendations. We are concerned that interventions provided outside of the evidence base could be unhelpful for people with PTSD. Excluding these groups from the guidance could mean that they are less likely to comply in the future.	Thank you for your comment. NICE guidance is primarily for NHS commissioned services, though other services may adopt it. NICE recognises the important role that the voluntary sector plays in the provision of care to many people.

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72.	SH	Association for the Advancement of Meridian Energy Techniques	3 6	72-73 151-156	Support for families and carers, practical and social support. EFT can be taught as a self-help technique within psycho-education group settings. Families and carers can feel empowered having this tool to deal with emotional challenges, at its simplest level a form of emotional first aid but which can be used in more depth. It is very flexible and low cost.	Thank you for your comment. We will consider all relevant published literature for the review question on providing support for families and carers. We will also consider the insight from service users who will be a part of the guideline committee.
73.	SH	True You Matrix	3	63	<p>Non-drug treatments and non-psychological approaches, such as Mindfulness, alternative and holistic approaches should be explored and included to ensure a whole person approach to PTSD and to enable integrated care models. More widely acceptable and tolerable treatments which have lower drop-out rates than current approaches (EMDR and trauma-focussed CBT) need to be found and included in the guidance.</p> <p>Trauma specialist Bessel van der Kolk advocates neurofeedback, mindfulness techniques, play, yoga. <a href="http://www.traumacenter.org/about/about_bessel.php">http://www.traumacenter.org/about/about_bessel.php</a></p> <p>Prof. Barbara Rothbaum from Emory University, Atlanta, USA is planning to include Acupuncture and Yoga in her program for veterans (personal communication at Colston Research Society Symposium on PTSD, Bristol, UK, November 2015) and is using virtual technology to treat PTSD.</p>	Thank you for the references. We will consider all high quality published literature in the review for treatments of those with PTSD and will review the references you have provided if they meet our criteria for inclusion.

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					<p><a href="http://emoryhealthcare.org/veterans-program/treatments-services/index.html">http://emoryhealthcare.org/veterans-program/treatments-services/index.html</a></p> <p>The scientific evidence for Dr. Berceli's Tension Release Exercises (TRE), as well as Emotional Freedom Technique (EFT) and Matrix Reimprinting (an advanced EFT approach) is growing.  <a href="http://traumaprevention.com/research/">http://traumaprevention.com/research/</a>  <a href="http://www.eftuniverse.com/research-and-studies/eft-research#ptsd">http://www.eftuniverse.com/research-and-studies/eft-research#ptsd</a></p> <p>Having attended a recent scientific symposium in Bristol, UK on PTSD (Colston Research Society Symposium 2015, New developments in PTSD research and treatment) with the main focus of finding pharmacological interventions even on an epigenetic level has made it clear to me, that we are far off from making a breakthrough in medical treatment of PTSD (if ever). In the meantime any promising alternative treatments must be explored with an open mind, to ensure patients receive the best treatment possible. Avoiding dependence on long-term medication is a high priority for most patients and their carers.</p>	
74.	SH	Association for the Advancement of Meridian Energy Techniques	3 4-5	64 98-121	<p>Psychological and psychosocial interventions</p> <p>We ask that the Guidance Development Team consider recommending the use of EFT (and other energy psychology</p>	Thank you for the references. We will consider all high quality published literature in the review for treatments of those with PTSD and will review the

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					<p>methods), or at the very least its introduction for the purpose of service evaluations and further research. Our request is based on evidence cited below, which has been hurriedly prepared and we will send a more comprehensive and targeted list as soon as possible but we would rather submit something than nothing before the 5<sup>th</sup> July 5pm deadline.</p> <p>Church D1, Hawk C, Brooks AJ, Toukolehto O, Wren M, Dinter I, Stein P. Psychological trauma symptom improvement in veterans using emotional freedom techniques: a randomized controlled trial. <i>J Nerv Ment Dis.</i> 2013 Feb;201(2):153-60. doi: 10.1097/NMD.0b013e31827f6351. <a href="http://www.ncbi.nlm.nih.gov/pubmed/23364126">http://www.ncbi.nlm.nih.gov/pubmed/23364126</a> Abstract: "This study examined the effect of Emotional Freedom Techniques (EFT), a brief exposure therapy combining cognitive and somatic elements, on posttraumatic stress disorder (PTSD) and psychological distress symptoms in veterans receiving mental health services. Veterans meeting the clinical criteria for PTSD were randomized to EFT (n = 30) or standard of care wait list (SOC/WL; n = 29). The EFT intervention consisted of 6-hour-long EFT coaching sessions concurrent with standard care. The SOC/WL and EFT groups were compared before and after the intervention (at 1 month for the SOC/WL group and after six sessions for the EFT group). The EFT subjects had significantly reduced psychological distress (p &lt; 0.0012) and PTSD symptom levels (p &lt; 0.0001) after the test. In addition, 90% of the EFT</p>	<p>references you have provided if they meet our criteria for inclusion.</p>

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					<p>group no longer met PTSD clinical criteria, compared with 4% in the SOC/WL group. After the wait period, the SOC/WL subjects received EFT. In a within-subjects longitudinal analysis, 60% no longer met the PTSD clinical criteria after three sessions. This increased to 86% after six sessions for the 49 subjects who ultimately received EFT and remained at 86% at 3 months and at 80% at 6 months. The results are consistent with that of other published reports showing EFT's efficacy in treating PTSD and comorbid symptoms and its long-term effects.”</p> <p>Karatzias, T., Power, K., Brown, K., McGoldrick, T., Begum, M., Young, J., . . . Adams, S. (2011). A controlled comparison of the effectiveness and efficiency of two psychological therapies for posttraumatic stress disorder: Eye Movement Desensitization and Reprocessing vs. Emotional Freedom Techniques. <i>Journal of Nervous and Mental Disease</i>, 199, 372–378. doi:10.1097/NMD.0b013e31821cd262</p> <p>“Overall, the results indicated that both interventions produced significant therapeutic gains at posttreatment and follow-up in an equal number of sessions. Similar treatment effect sizes were observed in both treatment groups. Regarding clinical significant changes, a slightly higher proportion of patients in the EMDR group produced substantial clinical changes compared with the EFT group.”</p>	

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75.	SH	Association for the Advancement of Meridian Energy Techniques	3 4-5	64 98-121	<p>Feinstein, D. (2012). Acupoint stimulation in treating psychological disorders: Evidence of efficacy. Review of General Psychology, 16, 364-380. doi:10.1037/a0028602... Available at:  <a href="https://innersource.net/ep/images/stories/downloads/Acupoint_Stimulation_Research_Review.pdf">https://innersource.net/ep/images/stories/downloads/Acupoint_Stimulation_Research_Review.pdf</a></p> <p>This is a review paper that showed that EFT met American Psychological Association (APA) criteria for “probably efficacious” therapy. Since publication (2012) later papers now provide sufficient evidence for EFT to meet APA criteria as “efficacious therapy” and APA allow continuous professional development credits for certain courses run by ACEP. Feinstein’s review considered 18 fully randomised controlled trials.</p> <p>“The 18 RCTs all meet established significance thresholds and showed strong effects in the 16 studies where effect size was calculated”.</p> <p>These 18 RCTs covered a range of anxiety-based conditions. “Four RCTs and five outcome studies that did not use a comparison group provide evidence on the efficacy of brief acupoint-assisted therapy in treating PTSD.” (EFT is an acupoint-assisted therapy)</p> <p>Al-Hadethe A, Hunt N, Al-Qaysi G, Thomas S (2015)</p>	<p>Thank you for the references. We will consider all high quality published literature in the review for treatments of those with PTSD and will review the references you have provided if they meet our criteria for inclusion.</p>

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					<p>Randomised Controlled Study Comparing Two Psychological Therapies for Posttraumatic Stress Disorder (PTSD): Emotional Freedom Techniques (EFT) Vs. Narrative Exposure Therapy (NET). J Trauma Stress Disor Treat 4:4. doi:<a href="http://dx.doi.org/10.4172/2324-8947.1000145">http://dx.doi.org/10.4172/2324-8947.1000145</a> Corresponding author: Ashraf Al-Hadethe, Division of Psychiatry and Applied Psychology, School of Medicine, The University of Nottingham, UK, "Methods: A randomized controlled trial design was used. Sixty Iraqi students were selected who met the DSM-IV PTSD criteria. Participants were male students who were aged between 16-19 years. Participants were randomly divided into three groups, with 20 participants in each group. Those in the EFT and NET groups received 4 therapy sessions, while the control group received no treatment. One person from the NET group withdrew. All participants were assessed on PTSD symptoms, anxiety and depression, social support." "Results: The results showed that the participants who received EFT reported a significant difference in all PTSD cluster at pre-test and post-test from T1 to T2 (<math>p&gt;0.05</math>). However, although the NET group reported a significant difference between pre-test and post-test in avoidance and re-experience, no significant</p>	

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					<p>difference was found in hyper arousal (<math>p &lt; 0.05</math>). However, no significant differences were found in the experiential group with social support, coping strategies, and religious coping (<math>p &lt; 0.05</math>). These changes of PTSD, PTSD clusters, anxiety and depression remained stable for 3, 6 and 12 month follow-ups in EFT group, while these changes were unstable during the follow-ups. Measures of coping strategies showed that seeking support and active coping improved since the interventions. In conclusion, both EFT and NET showed their effectiveness among traumatised Iraqi people."</p>	
76.	SH	British Association for Psychopharmacology	3	65	<p>The desire to make guideline recommendations fall within the licensed indications for medication is understandable but potentially misguided. The antidepressant venlafaxine does not have a licence for PTSD but one study with it is one of the largest and certainly the longest RCT, and in another it was numerically superior to sertraline in some outcome measures. Remember that the NICE guidance for generalised anxiety disorder (GAD) recommended first-line treatment with sertraline, even though it does not have a licence for GAD, so there is a precedent for making recommendations for an unlicensed application.</p>	<p>Thank you for raising this point. We will take it into account when considering which medications to review with the guideline committee.</p>
77.	SH	The Tuke centre	3	71	<p>Principles of care - there needs to be differentiation between the</p>	<p>Thank you for your comment. Thank</p>

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					principles of care for simple versus complex PTSD especially where comorbid presentations such as borderline PD and dissociation and these are very different in practice especially around risk management, support and stability work. Reference needs to be given to different steps for complex patients to include specialist unit approaches where treatment in a community setting is not achievable for risk or complexity purposes.	you for your comment. We will consider complex PTSD but do not agree that the terms should be used simultaneously throughout the scope.
78.	SH	BeTr Foundation	3	73	"Practical and social support" is too overgeneral a term if it points to the friends, family and interpersonal networks usually assumed to be helpful. No acknowledgement is made of the possibility that the social network could contain the triggers and threats that evoke posttraumatic stress reactions. A thorough explication on the role of various types of support and their optimal timing in the posttraumatic aftermath is long overdue if only because they are likely to precede any referral for PTSD assessment and treatment.	Thank you for your comment. We acknowledge your point that not all social networks are helpful for a person with PTSD. We will consider this in the development of our recommendations
79.	SH	East London NHS Foundation Trust	3	77	We believe that the recognition section could benefit from being updated to reflect the still poor rates of recognition in primary care and other front line services. In particular training and supervision for IAPT PWPs needs to be included as many first presentations may come through IAPT services. Training could also be increased for GPs and other professionals to improve recognition.	Thank you for your comment. The guideline will not be covering the recognition and diagnosis of PTSD. The NICE surveillance report concluded that the introduction of DSM-V for adults is unlikely to have an effect on the current diagnostic recommendations. And that there is

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## Post-traumatic stress disorder (update)

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						<p>currently a lack of data on validated screening tools. Whilst they acknowledged the impending release of ICD-11 will be significant, it is not due to be published until 2017/early 2018.</p> <p>Training is one factor that will be covered by review question 3.1: "For adults, children and young people with clinically relevant post-traumatic stress symptoms, what factors should be taken into account in order to provide optimal care, coordination of care and access to care?"</p>
80.	SH	The Intensive Care Society	3	78	The section on assessment of PTSD should arguably be updated, given that the definition of PTSD has been reviewed by the DSM-V (2013) and several PTSD assessment tools have been updated to include the new DSM-V criteria. The ICD-11 will also include a re-formulation of the entity of PTSD, and this should perhaps be considered in discussions of this guideline.	Thank you for your comment. The guideline will not be covering the recognition and diagnosis of PTSD. The NICE surveillance report concluded that the introduction of DSM-V for adults is unlikely to have an effect on the current diagnostic recommendations. And that that there is currently a lack of data on validated screening tools. Whilst they

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						acknowledged the impending release of ICD-11 will be significant, it is not due to be published until 2017/early 2018.
81.	SH	The Tuke centre	3	78	Areas not being updated - assessment. The current guideline in respect of assessment does not cover assessment of complex & multiple trauma presentations and where dissociation / dissociative disorders are present. Nor does it stress the importance of assessment for complex PTSD where a comorbid personality disorder such as borderline is present. For the guideline to now cover complex presentations this needs to be outlined as the using the same principles for single episode PTSD can lead to decompensation and increased risk in such patients especially where less experienced practitioners are completing the same. There should be guidance as to screening questions to identify simple vs complex cases with potentially increased risk and then direction as to which setting is most appropriate for the assessment of more complex patients e.g. IAPT or secondary care or specialist centres	Thank you for your comment. The guideline will not be covering the recognition and diagnosis of PTSD. The NICE surveillance report concluded that the introduction of DSM-V for adults is unlikely to have an effect on the current diagnostic recommendations and that that there is currently a lack of data on validated screening tools. Whilst they acknowledged the impending release of ICD-11 will be significant, it is not due to be published until 2017/early 2018.
82.	SH	BeTr Foundation	4	85-94	If, as it seems from the 2005 Guidelines, there are only 3-4 approaches to PTSD treatment economic analyses will be simple comparisons, and are to be encouraged as being economical in themselves; the Improving Access to Psychological Therapies programme shows how easily pre- and post-treatment scores can be displayed on a public website. It	Thank you for your comment. The Guideline Committee will consider the cost effectiveness of interventions and services for PTSD when making recommendations. We agree that interventions that are less effective but

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					should be borne in mind that more effective approaches than cognitive behaviour therapy (CBT) and eye-movement desensitisation reprocessing (EMDR) may exist but have not met NICE inclusion criteria. If a peer support protocol is 50% less effective than a clinical protocol but 90% cheaper it may still play an important role and be economically-justified.	produce considerable cost-savings may be more cost-effective options. Prioritisation of guideline review questions for economic analysis will take into account the anticipated magnitude of resource implications arising from potential recommendations.
83.	SH	BeTr Foundation	4	99-104	This should be undertaken in collaboration with educational psychologists, developmental psychologists and teachers for it to have any validity. The literature on children and young people has been a spin-off from the adult literature. Young people are not merely smaller adults; developmental processes have to be considered in this for any valid comment or recommendation is to be made.	Thank you for your comment, we have CAMHS practitioners on the guideline to enable us to address these issues
84.	SH	Helen Bamber Foundation	4	76	We are concerned that 'recognition' and 'assessment' are among the 'areas from the published guideline that will not be updated'. In light of the changes in DSM5 and the anticipated changes in ICD11 (which will come out well before the new guideline) these sections will need substantial updating	Thank you for your comment. The guideline will not be covering the recognition and diagnosis of PTSD. The NICE surveillance report concluded that the introduction of DSM-V for adults is unlikely to have an effect on the current diagnostic recommendations and that there is currently a lack of data on validated screening tools. Whilst they

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						acknowledged the impending release of ICD-11 will be significant, it is not due to be published until 2017/early 2018.
85.	SH	Helen Bamber Foundation	4	79	We are also concerned that the (very short) section on language and culture is also though not to be in need of updating. In light of the likely increase in the number of migrants and the emerging evidence on cultural differences in clinical presentation and on effective use of interpreters (and associated problems) should be incorporated into the updating process.	Thank you for your comment. We agree that language and culture are important. However this is a partial update and other areas were considered to be a higher priority for full review at the present time. However, factors such as language and culture will be considered by the guideline committee throughout the development process.
86.	SH	Association for the Advancement of Meridian Energy Techniques	4	84	Economic aspects. AAMET International is a small voluntary organisation run by consensus by volunteers promoting the use of EFT and establishing excellence in training, with over 100 trainers and some 1500 practitioner members worldwide. We all know from our personal experience with EFT that it has potential to save the NHS £millions or £billions. We would like to see that potential engaged to help with the suffering experienced due to mental health conditions as well as to deal with the financial challenges these conditions pose to our society and our health systems. But we are small (albeit passionate); we don't have access to health economists. We ask for health economist	Thank you for your comment. The Guideline Committee will consider the cost effectiveness of interventions and services for PTSD when making recommendations. Prioritisation of review questions for economic analysis will take into account the anticipated magnitude of resource implications arising from potential recommendations. Interventions that are found to be effective in the

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					<p>engagement to address the point made in the Clond meta-analysis cited below.</p> <p>Citation: Clond, M, Emotional Freedom Techniques for Anxiety. A systematic Review with Meta-analysis. Journal of Nervous and Mental Disorders 2016;204: 388–395, doi: 10.1097/nmd.0000000000000483 “This study found very high effect sizes for EFT treatment ...” “The effects observed in this meta-analysis” (pooled sample n=658) ...“can reasonably be expected to generalizable because of the variety of samples included and because of the use of a random-effects model, which usually makes a more conservative effect size estimate” “These data demonstrate that EFT therapy is associated with a significant treatment effect when patients are compared with baseline or compared with control conditions. There are insufficient data to demonstrate equivalence or superiority to traditional psychotherapy techniques such as CBT. However, because of its efficacy and ease of use, EFT may possess significant practical advantages to public health outcomes compared with resource-intensive approaches including CBT. Based on the positive outcomes, further studies are needed on patient satisfaction, patient preference, accessibility, cost saving, and comparison to standard of care.</p>	<p>guideline systematic review of clinical evidence may be further assessed for their cost effectiveness.</p>

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87.	SH	Helen Bamber Foundation	4	95	In the section on 'key issues and draft review questions' there should be a specific section on effective psychological and pharmacological treatments for 'complex PTSD' in addition to the breakdown by age and by duration of symptoms	Thank you for your comment. Complex PTSD has been included in 'who is this guideline for' and the evidence will be reviewed where it is available. The final review questions will be decided by the Guideline Committee.
88.	SH	Helen Bamber Foundation	4	95	The section on treatment will need a subsection on treatment of complex PTSD. In particular the need for more prolonged treatment in asylum seekers and refugees should be highlighted	Thank you for your comment. Complex PTSD has been included in 'who is this guideline for' and the evidence will be reviewed where it is available. Asylum seekers and refugees have also been included as a special population.
89.	SH	British Association for Psychopharmacology	4	102	The term 'clinically important reduction in symptoms' is used but there is no mention of the criteria that would be employed to make that judgement. It would be worth examining the change from baseline to endpoint on a disorder-specific psychopathological rating scale, the proportion of 'responders' (i.e. those with a 50% or greater reduction in symptom severity), the proportion of overall responders (on the basis of a clinical global impression of improvement score), and the proportion meeting a priori defined criteria for symptom remission.	Thank you for your comment. We will develop criteria to define "a clinically important reduction in symptoms", in collaboration with the GC.
90.	SH	The Tuke centre	4	117	There needs to be a clear differentiation for the approaches for simple versus complex PTSD including dissociative	Thank you for your comment. We agree that different types of presentation may

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					<p>presentations and where comorbid irises are present. Where there is no evidence this needs to be highlighted as an area of need for supported intervention research. Consideration needs to be given to different settings of treatment and frequencies of interventions e.g. Number of sessions per week.</p> <p>There should be reference to "stability work" within the treatment for those high risk patients and what evidence there is for effectiveness of this or if it is needed. The need for stability in patients with high risk behaviours is cited as barrier to treatment for trauma commencing yet the trauma symptoms are what drives the behaviours leaving the patient in a catch 22 situation. Where possible the guideline needs to look at this - of there is no evidence outline the need to research the same.</p> <p>Outcomes for high risk complex patients in different settings including inpatient approaches needs appraised in terms of individual outcomes, symptom load and economic cost. Highly complex patients who are high risk with complex PTSD / dissociation / borderline personality disorder have a high impact on services yet have little identified care and their needs are not currently covered in the guidance.</p>	<p>require different approaches, and this guideline aims to address these concerns where there is available evidence. Where evidence is not available we will be making research recommendations.</p>
91.	SH	BeTr Foundation	5	122-134	<p>We object to any pharmacological interventions for children and young people as a recommendation from NICE.</p>	<p>Thank you for your comment. NICE does not have a policy to not recommend pharmacological interventions where there is good evidence that the benefits outweigh the</p>

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						disadvantages. To do so would deny children effective interventions, which would be unethical.
92.	SH	BeTr Foundation	5	135-145	Pharmacological interventions should only be recommended where side-effects are made explicit so that a judgement can be made as to the wisdom of prescribing a drug in view of its iatrogenic effects.	Thank you for your comment. We agree that the assessment of pharmacological agents should also consider side effects.
93.	SH	BeTr Foundation	5	117-121	As above (5), more effective approaches than cognitive behaviour therapy (CBT) and eye-movement desensitisation reprocessing (EMDR) may exist but have not met NICE inclusion criteria. There is a listing process at the Substance Abuse and Mental Health Services Administration (SAMHSA) in the USA (the US Govt. Dept of Health and Human Services) with numerous approaches that have already met 'evidence-based' standards. The paucity of talking therapies (i.e., CBT and EMDR) in the 2005 Guidelines speak of a failure to consider other resources for effective approaches to psychological trauma. The SAMHSA standards, given its peer-review process for granting 'evidence-based' status, are set at a higher level than NICE and so justify consideration for previously unconsidered approaches.	Thank you for your comment. We will consider all high quality evidence on the treatment of PTSD.  We will include a section on research recommendations and if there is a consensus amongst the GC members that other treatments need RCTs, it may be raised here.
94.	SH	East London NHS Foundation Trust	5	117	We believe that "(including complex-PTSD)" should also be added after "For adults with PTSD" to ensure that complex-PTSD is included in the review questions. This is applicable to the whole of section 1.5 for each of the relevant review	Thank you for your comment. We will consider complex PTSD but do not agree that the terms should be used simultaneously throughout the scope

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					questions.	
95.	SH	BeTr Foundation	6	147-161	The social context, evidence of bullying, harassment, emotional abuse, neglect and physical violence. PTSD is unique due to its external cause so it seems naive, if not negligent, to treat it like the individual's problem.	Thank you for your comment.
96.	SH	First Person Plural	6	146-150	This paragraph is welcomed but will only be effective in practice for our beneficiaries, if the scope and resulting guidelines give direction about ensuring complex dissociative disorders have been ruled out before "clinically relevant post-traumatic symptoms" place the sufferer on a pathway of care for PTSD which might not be optimal if indeed the post-traumatic symptoms are being experienced within the dissociative framework of a dissociative identity disorder.	Thank you for your comment. Unfortunately we will not be covering diagnosis of PTSD in the update of the guideline. However, we acknowledge your point that people may be misdiagnosed with dissociative disorder and not receive the right treatment. We will be investigating the impact of dissociative symptoms in the presence of PTSD in the review question on comorbidities.
97.	SH	First Person Plural	6	157-161	Similarly this paragraph is welcomed but with all the caveats previously mentioned to ensure that people who have DID (currently recognised or not) either comorbid with PTSD or with misdiagnosed PTSD – do not get caught up on a non-optimal pathway of care for PTSD, because their DID has not been recognised or taken into account.	Thank you for your comment. Unfortunately we will not be covering diagnosis of PTSD in the update of the guideline. However, we acknowledge your point that people may be misdiagnosed with dissociative disorder and not receive the right treatment. We will be investigating the impact of dissociative symptoms in the presence

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						of PTSD in the review question on comorbidities.
98.	SH	The Tuke centre	6	157	There needs to be a specific reference to borderline personality disorder and dissociative disorders and ensure that the approaches for this particular highly problematic combination is addressed.	Thank you for your comment. We will be investigating the impact of dissociative symptoms and other mental health conditions in the presence of PTSD in the review question on comorbidities. The full list of comorbidities we will review will be decided by the GC.
99.	SH	BeTr Foundation	6	164	A definition of 'evidence' is crucial to a valid and reliable outcome. As a legal term, rather than a psychological one, it implies a hierarchy of quality that sometimes renders first-hand personal experience as "anecdotal" and therefore inadmissible, and randomised controlled trials (RCTs) as "gold standard" and therefore essential. A narrative statement of poor treatment is not mere anecdote and a poor-quality RCT is not good science. A detailed statement on the hierarchies of quality that represents 'evidence' is overdue and should be in plain-English expressed in probabilistic terms and, therefore, contestable.	Thank you for your comment. We agree, a poor RCT is not good science. We also acknowledge that RCTs are not always the best studies to use to answer some questions, such as patient experience. Thus the hierarchy of the evidence is dependent on the question. How we consider the evidence will be explained in detail in the methods. It is also worth noting, in the absence of high quality RCT evidence; we do consider the GC's experience and expertise that includes service users.
100.	SH	BeTr Foundation	6	165	The numerous revisions of the DSM criteria for PTSD make all	Thank you for your comment. We

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					assessments problematic and increasingly subjective. If symptoms of PTSD are sufficient markers to justify treatment then symptom counts (such as those listed in the Impact of Event Scale) should be as valid as those using specific PTSD scales which were only valid in the era they were created. This will increase the sweep of any review in identifying current (and previously overlooked studies) that may provide additional evidence for consideration.	recognise that the defining criteria for PTSD has varied over time and this will have an impact on the inclusion or exclusion of evidence. This guideline includes complex PTSD and we will consider all relevant literature in the update of this guideline
101.	SH	BeTr Foundation	6	166	If 'recovery' is an acceptable outcome then 'posttraumatic growth' should be too. This is a psychological state that is functionally superior to that of recovery. Growth, despite its widespread acknowledgement in different religions, cultures and post-disaster media stories does not even arise in the 2005 Guidelines. Posttraumatic growth is surely the optimal outcome to surviving a traumatic experience and with the literature consistently reporting its emergence its inclusion in NICE consideration is justified.	Thank you for your comment. The list in the scope is not the final list of outcomes that will be included in the reviews. We will discuss the relevance of different outcomes with the GC, including posttraumatic growth.
102.	SH	BeTr Foundation	6	168	Relapse should be considered not merely as a patient-problem but as a failure of treatment, unexpected iatrogenic effects and the prospect of an incompetent clinician.	Thank you for your comment.
103.	SH	BeTr Foundation	6	169	The carer experience should include the clinician, the treatment team, friends, family and the social support network if it is to have any relevance. Another aspect of exposure to posttraumatic stress missing from the 2005 Guidelines is 'secondary' or 'vicarious traumatising'. The assumption that	Thank you for your comment. The list in the scope is not the final list of outcomes that will be included in the reviews. We will discuss the relevance of different outcomes with the GC,

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					the findings of a controlled study will translate its effects into the clinical population at no cost to those living and working with those affected does little to enhance our understanding of the persistence of PTSD in the community.	including friends, family and social support related outcomes.
104.	SH	East London NHS Foundation Trust	6	174	Drop-out rates and engagement with treatments would be a helpful outcome to include. These may need specifying above and beyond "Acceptability of the intervention".	Thank you for your comment. The list in the scope is not the final list of outcomes that will be included in the reviews. We will discuss the relevance of different outcomes with the GC, including drop-out rate and engagement with treatment.
105.	SH	British Association for Psychopharmacology	6	174	The term 'acceptability' is used without clarification of its meaning. You could look at the profile of reported adverse effects, although this aspect of treatment is often overlooked in psychological interventions; and also perhaps at overall drop-out rates, after say 1 week, 1 month, and 3 months of treatment (regardless of treatment modality).	Thank you for your comment. We have adverse effects of treatment as one of the major outcomes to include.  We will discuss with the GC how acceptability is best defined and whether this may include drop-out rates. .
106.	SH	Helen Bamber Foundation	7	177	It would be helpful to emphasise the particular difficulties that people with complex PTSD and trust-related difficulties will have in accessing appropriate care. This might appropriately be placed in the section on links with other NICE guidelines and, in particular, in relation to the guideline on the patient experience in adult NHS services	Thank you for your comment. We have made reference to the patient experience guideline in the scope and will do so in the updated guideline.  We have also included a review

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						question on how to improve access to care given the difficulties that people with PTSD and complex PTSD have in accessing the appropriate services. .
107.	SH	Helen Bamber Foundation	9	235	In the section on key facts and figures, reference should be made to increased risk (with corresponding prevalence rates) in asylum seekers and in the prison and immigration detention settings and, more generally in migrants.	Thank you for your comment. This section is not intended to provide an exhaustive list of at-risk populations. However refugees have been listed on line 242.
108.	SH	Helen Bamber Foundation	9	235	In light of the Modern Slavery Act, it would also be timely to emphasise the high prevalence of PTSD in victims of human trafficking	Thank you for your comment. This section is not intended to provide an exhaustive list of at-risk populations. We have included people who have experienced interpersonal violence or sexual assault on lines 242 and 243, which are of relevance to many victims of human trafficking.
109.	SH	The Tuke centre	9	236 onwards	Context paragraph – this only covers the presentation of simple PTSD and does not look to make any comment on complex presentations incl where personality disorder and or dissociative disorders are present. For the guideline to address these presentations as well this needs to be altered,	Thank you for your comment. Complex presentations, including co-morbidities, are specifically referenced in lines 302-307 of the context section. The guideline will be covering the groups that you describe. A question on comorbidities has been included lines 157-161.

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110.	SH	The Tuke centre	9	256	Current practice – this is only relevant to the treatment of simple trauma, complex cases are referred to IAPT only to be re-referred in secondary care where there are limited services. One of the most important impacts on patient care the new guideline can bring is the differentiation of where the different cases should be treated to avoid patients being unnecessarily pushed from one service to another. The lack of differentiation is a barrier to treatment for complex patients and means a lack of investment into services with experienced clinicians to treat these cases and the support needed around them. This section also needs to include reference to care approaches for those who's presentation and risk means they cannot be managed in the community.	Thank you for your comment. This was an omission, and we have now updated this section to include reference to adult community mental health teams and inpatient services.
111.	SH	First Person Plural	10	270-275	The trauma-focused psychological treatments described once again support our arguments that differential diagnosis to identify people who have dissociative identity disorder needs to be given greater emphasis in the scope and resulting guideline. A phased model of psychological treatment which includes extensive stabilisation work before any trauma work is attempted is recommended by the International Society for the Study of Trauma and Dissociation guidelines for the treatment of dissociative identity disorder, and by the European Society for Trauma & Dissociation's child & adolescent guidelines. (There are no NICE guidelines for DID) When people who have dissociative identity disorder end up on a PTSD care pathway	Thank you for your comment. We agree that dissociative identity disorder is a separate condition and as such although dissociative symptoms will be covered by this guideline, dissociative identity disorder will not be.

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					the treatment can be damaging and is not effective.	
112.	SH	First Person Plural	10	247-250	We suggest an additional insertion after these sentences thus... “Conversely, sufferers of other even less well recognised trauma-related conditions such as dissociative identity disorder, are sometimes wrongly or incompletely labelled as having PTSD, without recognition of their complex dissociative disorder. In this context referrals for PTSD treatment can be made inappropriately, resulting in ineffective and possibly damaging outcomes” For this reason it is essential that full differential diagnosis is emphasised in this scope and resulting guidelines.	Thank you for your comment. The subject of this guideline is PTSD rather than other trauma-related conditions. As such we are not able to make his amendment.
113.	SH	First Person Plural	10	266-269	The access to services described here is another reason why we feel the scope should place greater emphasis on differential diagnosis – particularly, from our point of view, to ensure that people who have significant symptoms of post traumatic symptoms but who also have dissociative identity disorder or similar complex trauma-related dissociative condition, are not left to languish in a queue for a service for PTSD which is not going to be effective for them.	Thank you for your comment. This guideline is concerned with the treatment of PTSD, and will include dissociative symptoms, but not dissociative identity disorder. We appreciate your concerns relating to accurate identification; however recognition and assessment is not the subject of this partial update of the guideline, which is concerned purely with treatment.
114.	SH	The Association for Dance Movement Psychotherapy	10	267	The draft scope currently includes “psychological therapies” as an intervention. We feel that this needs a clearer definition such as adding “ including talking and Arts Psychotherapies” because at the moment CBT and EMDR are listed separately, whereas	Thank you for the references. We will consider all relevant literature in the update of this guideline and will review the references you have provided if

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					<p>the Arts Psychotherapies including Art, Drama, Music, and Dance Movement may also be beneficial and a cost effective intervention for this client population.</p> <p>Dance movement psychotherapists are qualified practitioners, trained for a minimum of three years at a Masters' level. Qualified dance movement psychotherapists emphasise the non-verbal and creative aspects of relating within an agreed and safe relationship.</p> <p>Some examples of relevant research study are included here in case this is helpful.</p> <p>Cochrane Systematic Review:</p> <p>Meekums B, Karkou V, Nelson EA. Dance movement therapy for depression. Cochrane Database of Systematic Reviews 2015, Issue 2. Art. No.: CD009895. DOI: 10.1002/14651858.CD009895.pub2.</p> <p>The review recommended the need for further research. <a href="http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009895.pub2/abstract">http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009895.pub2/abstract</a></p> <p>Meta-analyses:</p> <p>Koch S, Kunz T, Lykou S and Cruz R (2014) Effects of dance</p>	<p>they meet our criteria for inclusion. We have not specified interventions within the review questions, which allow us scope to include any interventions that the guideline committee identify as relevant. Arts therapies would be captured under the category of 'psychosocial interventions'.</p>

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## Post-traumatic stress disorder (update)

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					<p>movement therapy and dance on health-related psychological outcomes: A meta-analysis, <i>The Arts in Psychotherapy</i>, 41, 46-64. <a href="http://www.sciencedirect.com/science/article/pii/S0197455613001676">http://www.sciencedirect.com/science/article/pii/S0197455613001676</a></p> <p>Randomized controlled trial <u>Bräuninger, I. (2012) Dance movement therapy group intervention in stress treatment: A randomized controlled trial (RCT) <i>The Arts in Psychotherapy</i> Volume 39, Issue 5, November 2012, Pages 443–450</u></p> <p>Systematic Literature Reviews:</p> <p>Strassel, J.K., Cherkin, D. C., Steuten, L., Sherman, K.J., &amp; Vrijhoef, H.J.M. (2011). A systematic review of the evidence for the effectiveness of dance therapy. <i>Alternative Therapies in Health &amp; Medicine</i>, 17(3), 50–59.</p> <p>Dance Movement Psychotherapy</p> <p>Pierce, L. (2014), "The integrative power of dance/movement therapy: Implications for the treatment of dissociation and developmental trauma", <i>The Arts in Psychotherapy</i>, vol. 41, no. 1, pp. 7-15.</p>	

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					<u>Koch</u> . S.C. (2009) Traumatized refugees: An integrated dance and verbal therapy approach <u>The Arts in Psychotherapy</u> Volume 36, Issue 5, November 2009, Pages 289–296	
115.	SH	The Association for Dance Movement Psychotherapy	10	267	<p>Tin Hung H. R. 2015 A place and space to survive: A dance/movement therapy program for childhood sexual abuse survivors <u>The arts in psychotherapy</u> 46</p> <p>Neuroscientific research The role of embodiment within psychotherapy is currently receiving renewed attention from neuroscientists. For example, research studies in neuroscience provide evidence for the biological basis of emotion and the links between body and feelings (Damasio 1994, 2000); the plasticity of the brain and thus a life-long ability for humans to make new synaptic connections (Edelman 1987); the role of mirror neurons in the brain and their links with empathy (Rizzolatti et al 1996; Gallese 2003; Gazzola et al 2006).</p> <p>Neuroscientific research, dance movement psychotherapy and relationships</p> <p>Within dance movement psychotherapy, the following empirical</p>	Thank you for the references. We will consider all relevant literature in the update of this guideline and will review the references you have provided if they meet our criteria for inclusion.

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					<p>studies offer evidence on the impact of kinaesthetic empathy on the brain:</p> <p>Rova, M. (2012-2015) <i>Embodying Kinaesthetic Empathy as an Intersubjective Phenomenon and Clinical Intervention: a practice-based interdisciplinary study combining Dance Movement Psychotherapy, Phenomenology and Cognitive Neuroscience</i>. London: University of Roehampton (PhD research)</p> <p>Fischman, D. (2009) <i>Therapeutic Relationships and Kinesthetic Empathy</i> in Chaiklin, S. &amp; Wengrower, H. (Eds.). <i>The Art and Science of Dance/Movement Therapy: Life is Dance</i>. New York/London: Routledge <a href="http://www.torontopubliclibrary.ca/detail.jsp?R=2681347">http://www.torontopubliclibrary.ca/detail.jsp?R=2681347</a></p> <p>McGarry, M. L. &amp; Russo, F.A. (2011) <i>Mirroring in dance/movement therapy: Potential mechanisms behind empathy enhancement</i>. <i>The Arts in Psychotherapy</i>, 38, 178-184 <a href="http://www.sciencedirect.com/science/article/pii/S0197455611000426">http://www.sciencedirect.com/science/article/pii/S0197455611000426</a></p> <p>Beausoleil, E. &amp; LeBaron, M. (2013), "What Moves Us: Dance and Neuroscience Implications for Conflict Approaches: What Moves Us", <i>Conflict Resolution Quarterly</i>, vol. 31, no. 2,</p>	

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					pp. 133-158.  Fonagy, P. & Target, M. (2007), "The Rooting of the Mind in the Body: New Links Between Attachment Theory and Psychoanalytic Thought", Journal of the American Psychoanalytic Association, vol. 55, no. 2, pp. 411-456.	
116.	SH	The Association for Dance Movement Psychotherapy	10	267	Other Arts Psychotherapies Carr, C., d'Ardenn, P., Sloboda, A., Scott, C., Wang, D. and Priebe, S. 2012, Group music therapy for patients with persistent post-traumatic stress disorder – and exploratory randomized controlled trial with mixed method evaluation Psychology and psychotherapy: Theory, Research and Practice 85  Bensimon, M., Amir, D. and Wolf, Y. 2012 A pendulum between trauma and life: group music therapy therapy with post-traumatized soldiers The arts in psychotherapy 39  Lahad, M., Farhi, M., Leykin, D. and Kaplanski, N. 2012 Preliminary study of a new integrative approach in treating post-traumatic stree disorder: SEE FAR CBT The arts in psychotherapy 37  Pretorious, G and Pfeifer, N. 2010, Group art therapy with	Thank you for the references. We will consider all relevant literature in the update of this guideline and will review the references you have provided if they meet our criteria for inclusion.

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					sexually abused girls South African journal of psychology, 40 (1)  Leitch, M. L. 2007 Somatic Experiencing Treatment with Tsunami Survivors in Thailand: Broadening the Scope of Early Intervention Traumatology Vol.13 (3)	
117.	SH	East London NHS Foundation Trust	10	269	We feel it would be helpful to include a comment about training and supervision for IAPT services as some of this may be provided by specialist trauma services.	Thank you for your comment. We may comment on supervision as it relates to the treatment of PTSD but not generally on IAPT services.
118.	SH	Greater Manchester West Mental Health Foundation NHS Trust	10	270	The draft scope currently excludes more recent evidence based treatments (Metacognitive Therapy). Outcome data of this new treatment looks promising. The originator of Metacognitive therapy is Prof Adrian Wells. Whilst this is not a call for evidence. The evidence to date from this treatment could impact on costs.	Thank you for your comment. We will consider all relevant literature in the update of this guideline. We have not specified interventions within the review questions, which allows us scope to include any interventions that the guideline committee identify as relevant. Metacognitive therapy would be captured under psychological and psychosocial therapies, which are listed within the draft review questions.
119.	SH	British Association for Psychopharmacol	10	270	A statement is made that CBT and EMDR are the most common treatments for PTSD symptoms in adults. I am not aware of the evidence to support this contention: a number of patients who	Thank you for this comment. The intention was to focus on treatments recommend for PTSD, SRRIs and other

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		ogy			receive SSRI and other antidepressants do so for the reason of PTSD, so it would be worth examining reported indications in primary care prescribing data to establish how frequent this is.	antidepressants are not recommended in the current NICE guideline as first line treatments for PTSD
120.	SH	British Association for Psychopharmacology	11	283	The note that 'parallel treatment models' have been developed to treat patients with comorbid PTSD and substance use disorders is a reflection of clinical necessity. It would certainly be worth examining the data from all treatment studies to see how the sub-group of patients with this comorbid condition fares, when compared to patients with 'pure' PTSD, for both psychological and pharmacological treatment interventions.	Thank you for your comment. We have included a review question relating to comorbid conditions.
121.	SH	East London NHS Foundation Trust	11	285	The section on current practice needs to include the current provision of services for people with PTSD following repeated trauma and/or with complex PTSD. Although the 2005 guideline did not include these groups, the Context section for this guideline's scope should include current clinical practice for this group as they are included in the update guideline.  Specialist trauma services are mentioned in the "Legislation, regulation and guidance" section. However, their role in the current provision of services, and also the provision of care from secondary care and personality disorder services is important to include in section 3.2. In a survey carried out by the Institute of Psychotrauma in 2014, 12 specialist trauma services were identified in the UK. These included services focused on specific groups such as veterans or clients with a borderline PD	Thank you for your comment. Within the context of a lack of an agreed definition of complex PTSD and associated data on prevalence and treatment, we do not believe it is possible to provide a summary of the current treatment options.

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					diagnosis. There may be additional services now.	
122.	SH	East London NHS Foundation Trust	11	298	We feel it would be important to include a reference to people going through the criminal justice system here. It would be helpful for the final guideline to contribute to the guidance on delivering pre-trial therapy for people with PTSD who are involved in court proceedings.	Thank you for your comment. People with PTSD within the criminal justice system are considered in the NICE guideline on Mental Health in the Criminal Justice System, which is currently in development.
123.	SH	East London NHS Foundation Trust	11	305	The service at the Maudsley is not the only specialist service for people with treatment resistant PTSD or complex PTSD, so it seems inequitable to include just one example where other national services exist.	Thank you for your comment. We have removed the reference to the Maudsley hospital.

None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry

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