Institution:
Edinburgh Napier University

Unit of Assessment:
Unit of Assessment 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study:
Complex Posttraumatic Stress Disorder and the International Trauma Questionnaire: Achieving global recognition of a new condition, and improving assessment and treatment

Period when the underpinning research was undertaken:
2013-2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Thanos Karatzias	Professor and School Head of Research	2004 - Present

Period when the claimed impact occurred:
2018-2020

Is this case study continued from a case study submitted in 2014?
N

1. Summary of the impact (indicative maximum 100 words)

Research at Edinburgh Napier University (ENU) contributed to the World Health Organisation's (WHO) classification of a new disorder, Complex Post-Traumatic Stress Disorder (CPTSD), a streamlined PTSD diagnosis, and to the development of the only globally recognised and utilised tool for their assessment, the International Trauma Questionnaire (ITQ). The ITQ is freely available online and it has been translated in 22 languages. Healthcare providers and charities across the world now use the ITQ for the assessment of PTSD and CPTSD. Its use is recommended by the President of the UK Psychological Trauma Society and the lead of the Royal College of Psychiatrists for refugee and asylum mental health, amongst other healthcare leaders globally.

The ITQ has improved patient assessment and diagnosis internationally. A global survey of 35 organisations across 16 countries estimated that the ITQ had been used for 2,051 new patient referrals, and 1,087 existing patient referrals. The true reach of the ITQ is far wider. Leading medical specialists have confirmed the utility of the ITQ, as have charity employees working with military veterans, asylum seekers and other traumatised populations.

2. Underpinning research (indicative maximum 500 words)

Post-Traumatic Stress Disorder (PTSD) is a condition that has historically defied simple diagnosis. Patients often display a range of symptoms such as flashbacks and interpersonal problems, and categorizing them under the umbrella of PTSD can be problematic. As a consequence, many people with traumatic distress have not met the criteria of the traditional PTSD diagnosis, and have been unable to access appropriate treatment. In 2013, the World Health Organisation (WHO) appointed a stress disorder working group, which proposed a more streamlined assessment of PTSD based on three core symptoms (re-experience, avoidance and hyperarousal). It also proposed the recognition of a completely new 'sibling' disorder; CPTSD. In broad terms, PTSD can be defined as arising from a single traumatic event, while CPTSD is the result of repeated and childhood traumatic events. The working group required empirical confirmation of the two proposed conditions to ensure they fully understood the implications of their recommendation, and were able to confirm the new disease structure. To achieve this, they consulted research produced by experts in the field, including Professor Karatzias.

In 2016, Prof. Karatzias led the first study in the world that used a new measure to describe traumatic stress in terms of PTSD and CPTSD according to ICD-11 descriptions. This took place in collaboration with NHS Lothian Rivers Centre for Traumatic Stress in a cohort of patients with traumatic stress **[O1]**. The results validated the working group's proposals, which were adopted in the 11th revision of WHO International Classification of Diseases (ICD-11) in 2018. The next focus of the ENU research was the development of a robust tool for CPTSD diagnosis using the new classification parameters. Helping to finalise the development of a new tool by deciding the final list of PTSD and CPTSD symptoms, Prof. Karatzias was able to further elucidate the meaning and structure of CPTSD and suggest a streamlined PTSD diagnosis. The aim of the new tool is to improve mental health screening of patients for PTSD and CPTSD. Prof. Karatzias was part of the research team that standardised the scale and published it as the International Trauma Questionnaire (ITQ). The ITQ is freely available at online and it has been translated in 22 languages. The instrument was standardised on UK population-based clinical data that he collected **[O2]**. This research confirmed a novel and effective way of diagnosing an entirely new condition (CPTSD), greatly enhancing the potential for treatment and recovery among thousands of sufferers. Further epidemiological work in the UK population followed (led by Karatzias), which confirmed that CPTSD is a more common and more comorbid condition that PTSD. **[O3]**.

Prof. Karatzias has repeatedly tested the replicability of these findings all over the world. As an example, in 2019, the ITQ was used by the research team to assess the replicability of PTSD and CPTSD cross-culturally, in samples from Germany, Israel, the UK and the US **[O4].** The study found that despite differences in traumatic experience and culture, the structure of PTSD and CPTSD symptoms is similar across international boundaries, supporting the international applicability of ICD-11, which is used as the official diagnostic tool in 192 countries worldwide. Professor Karatzias has also undertaken similar work in Asia and Africa to confirm the validity of ICD-11 PTSD and CPTSD diagnoses using the ITQ. Each international study has confirmed significant numbers of CPTSD sufferers under the new diagnosis.

More recently, Prof. Karatzias concentrated his efforts on the validity of PTSD and CPTSD in hard to reach populations who are highly traumatised. In 2020 Professor Karatzias contributed to a study concerning UK veterans which aimed to assess the use of the tool with this group, which have typically responded poorly to traditional PTSD treatment **[O5]**. The study confirmed that CPTSD was more common than PTSD, and as well as confirming the utility of the ITQ, proposed new pathways of care and treatment. A similar project was undertaken in 2020 with UK male prisoners **[O6]**, which again confirmed the two distinct disorders. Currently Prof. Karatzias, is confirming the validation of the ITQ in children and young people, and he is working on new treatments for CPTSD as evidence suggests that existing effective therapies for PTSD are not effective for CPTSD.

3. References to the research (indicative maximum of six references)
All outputs **[O1-O6]** have been published following rigorous peer review.

[O1] Karatzias T, Shevlin M, Fyvie C, Hyland P, Efthymiadou E, Wilson D, Roberts N, Bisson J, Brewin C R, Cloitre M. *Evidence of Distinct Profiles of Posttraumatic Stress Disorder (PTSD) and Complex Posttraumatic Stress Disorder (CPTSD) based on the New ICD-11 Trauma Questionnaire*. (2016). Journal of Affective Disorders, 207. http://dx.doi.org/10.1016/j.jad.2016.09.032 **Submitted to REF2**.
[O2] Cloitre M, Shevlin M, Brewin C R, Bisson J I, Roberts NP, Maercker A, **Karatzias T**, Hyland, P. *The International Trauma Questionnaire: development of a self-report measure of ICD-11 PTSD and complex PTSD.* (2018). Acta Psychiatrica Scandinavica, 138 (6). http://dx.doi.org/10.1111/acps.12956. **Submitted to REF2**.
[O3] Karatzias T, Hyland P, Bradley A, Cloitre M, Roberts NP, Bisson JI, Shevlin M. *Risk factors and comorbidity of ICD-11 PTSD and complex PTSD: Findings from a trauma-exposed population-based sample of adults in the United Kingdom*. (2018). Depression and Anxiety, 36 (9). http://dx.doi.org/10.1002/da.22934 **Submitted to REF2**.
[O4] Knefel M, **Karatzias T**, Menachem B, Cloitre M, Lueger-Schuster B, Maercker A. *The replicability of ICD-11 complex post-traumatic stress disorder symptom networks in adults*.

(2019). British Journal of Psychiatry, 214 (6). https://doi.org/10.1192/bjp.2018.286. **Submitted to REF2**.
[O5] Murphy D, Shevlin M, Pearson E, Greenberg N, Wessely S, Busuttil, W (2020). **Karatzias. T**. *A validation study of the International Trauma Questionnaire to assess ICD-11 posttraumatic stress disorder (PTSD) in treatment seeking veterans*. (2020). British Journal of Psychiatry, 216 (3), 132 137. DOI: 10.1192/bjp.2020.9
[O6] Facer-Irwin E., **Karatzias T**., Bird A, Blackwood N, MacManus D. *PTSD and complex PTSD in sentenced male prisoners in the UK: prevalence, trauma antecedents, and psychiatric comorbidities*. (2020). Psychological Medicine. In press. DOI: 10.1017/S0033291720004936

4. Details of the impact (indicative maximum 750 words)
The research underpinned the new classification of two conditions, PTSD and CPTSD, which were included in the World Health Organisation (WHO) ICD-11. This led to the creation and validation of a reliable tool to screen for them. The beneficiaries included the WHO, healthcare providers and charities and patients.

The impacts can be summarised under three headings:
- Definition of a new condition (CPTSD) in ICD-11.
- Provision of a more effective framework and assessment tool for PTSD and CPTSD
- Improved care for patients with PTSD and CPTSD

Definition of a new condition (CPTSD) in ICD-11: Research into the ICD-11 classification of PTSD / CPTSD **[O1]** and development of the ITQ **[O2]** took place concurrently. The early versions of the ITQ were used to substantiate and develop the evidence base on the symptom structure of CPTSD. This helped to elucidate the meaning and structure of the new disorder and decide its final symptoms. As a result, the WHO included the new conditions in ICD-11 in 2018. Since 2018 ICD-11 is a global standard for diagnosis, the ITQ is now the default tool for diagnosis of PTSD and CPTSD, and is approved for screening across all 192 WHO member states.

The Chair of the 2018 Working Group on the Classification of Trauma and Stress Related Disorders, (for the development of the 11th revision ICD-11 by the WHO), wrote, "*The resulting work of the group included a new diagnostic category, Complex Post-Traumatic Stress Disorder…Professor Karatzias has contributed to this work by providing expertise in the areas of clinical expertise related to trauma and assessment, and was among the key developers of the International Trauma Questionnaire (ITQ) [..] Since the release of the ICD-11 in June 2018 the final version of the ITQ has been used extensively and is, to date, the only self-report measure of CPTSD that is consistent with the diagnostic description as stated in the ICD-11. Overall the ITQ played an important role in strengthening the research basis for this new disorder. The development of the ITQ has supported the work of the WHO in recognising CPTSD as a distinct psychological disorder."* **[C2]** (2020).

The ITQ has been adopted by mental health services and researchers globally as a result of the research confirming its validity and the WHOs adoption of PTSD and CPTSD as recognised conditions **[O3]**. In an impact report (2020) by Ulster University **[C1]**, representatives of 35 organisations in 16 countries confirmed they used the ITQ. 83% responded that they had used a different measure previously and 89% of users confirmed the ITQ had a measurable benefit on their work.

Provision of a more effective framework and assessment tool for PTSD and CPTSD: Confirmation of the ITQ as a reliable and valid tool **[O1, O2, O3]** for the assessment of PTSD and CPTSD in various cultures and population groups **[O4, O5, O6]**, led to healthcare providers utilising it for service improvement. The impact report **[C1]** showed that 39 users of the ITQ in 18 countries identified 111 clinicians using the tool within their organisations.

The report also confirmed that, within the sample, organisations had used the ITQ for research on approximately 50,000 participants. Approximately 500 healthcare students had received

training on how to administrate the tool. Considering the sample size and the fact that the ITQ is the only assessment tool for ICD-11 PTSD and CPTSD diagnosis, its global reach in terms of its benefit to patients is significant.

The impact and benefits on individual clinical practice and healthcare providers has been significant. Health care professionals, in the UK and abroad, have detailed the importance of the tool to their practice. The Lead Clinician for the Traumatic Stress Service at Cardiff and Vale University Health Board commented "*The ITQ is used in our service in three different ways: as an assessment tool for patients; as an outcome measure in our clinical service; and as an outcome measure in research. We use the ITQ to assess approximately 300 patients per year in the clinic [..] the ITQ is useful as it is the only measure that is scientifically structured to evaluate ICD-11 PTSD and Complex PTSD. The ability to recognise Complex PTSD has important treatment implications regarding targeting and improving symptom clusters"* **[C10]** (2020). A Consultant Clinical Psychologist at the Department of Psychotraumatology at the Clinic St. Irmingard, Germany noted "*I began using the ITQ about a year ago, and have assessed around 100 people using the tool thus far. We use the ITQ to routinely assess for ICD-11 PTSD and complex PTSD in our clinic [..] As an inpatient treatment facility focused on treating the most severe cases of PTSD, we lacked the ability to diagnose Complex PTSD [..] The ITQ is a much more economical method of assessing Complex PTSD, and is much more focused on the problems our patients have"* **[C8]** (2020).

The ITQ has been frequently used at a number of important national and international mental health settings that provide services to community, military, and refugee populations with traumatic stress. The Medical Director at the Helen Bamber Foundation (a human rights organisation), who is also the Royal College of Psychiatrists lead on refugee and asylum health noted "*We began using the ITQ in 2018 and have used it to assess approximately 400 patients[..] The ITQ has provided diagnostic clarity [..] the measure provides a useful focus for clinical discussion and has implications for treatment. The ITQ acts as an instrument for arguing that a person has complex and long-term therapeutic needs'* **[C3]** (2020). The President of the UK Psychological Trauma Society and Head of Research at veterans' charity Combat Stress stated in 2020 that, "*The ITQ was used in a service redesign at Combat Stress as a new and better way of exploring Complex PTSD [..] The ITQ was integrated into our routine assessment [..] since then all new referrals have been assessed using the ITQ [..] Using the ITQ at Combat Stress has allowed the psychology staff a more nuanced assessment of the symptoms of Complex PTSD. Its use has led to a formal way of describing complex PTSD rather than relying on clinical judgment, and has introduced new treatment paths at Combat Stress."* **[C6]**.

Improved care for patients with PTSD and CPTSD: The description of CPTSD as a new condition, the development of the ITQ **[O1, O2, O3]**, and the confirmation of its utility with vulnerable groups **[O5, O6]** have led to an increase in the quality of service provision (assessment and subsequent treatment) for individuals with PTSD and CPTSD. The impact report **[C1],** indicated that since the publication of the ITQ in 2018 it had been used by the 35 respondents in 16 countries to assess 2,051 new patient referrals and 1,087 existing patient referrals. 507 of the clients were reported as having their treatment outcomes evaluated using the ITQ.

Use of the ITQ has also improved patient care. The Head of the Rivers Centre, a specialist trauma service in NHS Lothian, noted in 2020, *"We have assessed approximately 2,050 people with the ITQ [..] I have experience using the ITQ in a face-to-face capacity with clients. I have noticed that [..] those who complete the ITQ find it to be quite a validating process. When completing the ITQ, they see in front of them a good description of the difficulties they struggle with. This helps people to feel that they are in the right place for treatment'* **[C4]**. Further, a clinical psychologist in a psychiatric speciality department at Uppsala University Hospital, Sweden wrote "*I have personally used the ITQ in a clinical capacity with around 25 patients, but am aware of around 55 other patients in the facility who have been assessed using the ITQ by other clinicians [..] Complex PTSD has a complicated history in Sweden [..], and may have a reputation for suggestive and poor-quality treatments. We are trying to change that as the ICD-*

11 now finally has a set definition for Complex PTSD [..] and the ITQ is a necessary tool to assess that” **[C7]** (2020). A National Psychological Therapies Lead at Traumatic Stress Wales stated “*In my personal work I used the ITQ with around thirty patients to assess for PTSD/Complex PTSD and to evaluate their treatment outcomes [..] we expect to see different types of population groups such as refugees and asylum seekers in the service; the ITQ has previously been validated in these populations. Its hugely important to be able to have a measure that recognises different clusters of symptoms related to trauma, allowing clinicians to really target those symptoms within interventions”* **[C5]** (2020).

The ITQ also has international reach beyond state and private healthcare. Commenting on the success of the tool in veteran populations **[O5]**, a staff member at the National Centre for PTSD Division of Dissemination and Training within the US Department of Veterans Affairs noted “*As a clinician I have used the ITQ in several ongoing clinical trials and evaluation programs among community and veteran populations [..] patients have responded in a highly positive manner to the ITQ. Patients may not have a clear understanding or ability to easily articulate the full range of problems they experience, but once presented in the ITQ, have remarked on their satisfaction with the measure and sense of validation regarding their symptoms’* **[C9]** (2020). A former employee at the International Medical Corps, one of the world’s largest humanitarian first responder charities stated “*We have used the ITQ since 2018 when we translated it, adapted it, and validated it in Arabic. In my clinical practice, I have used the ITQ in approximately 60 assessments. We [..] were working with one of the largest ever refugee populations in Syria that did not speak English [..] Our research validating the ITQ found that approximately 65% of the population sampled (110 Syrian refugees) had PTSD or Complex PTSD)* **[C11**] (2020).

5. Sources to corroborate the impact (indicative maximum of 10 references)

[C1] – ITQ Impact Case Study Research Report –Ulster University (2020)
[C2] – Letter from Chair of the 2008 Working Group on the Classification of Trauma and Stress Related Disorders for the development of the 11th Revision of the International Classification of Diseases (ICD-11) by the World Health Organisation (WHO).
[C3] – Letter from the Medical Director of the Helen Bamber Foundation and leader of the Royal College of Psychiatrists on refugee and asylum mental health.
[C4] – Letter from the former Head of Services at the Rivers Centre, a specialist trauma centre in NHS Lothian.
[C5] – Letter from the National Psychological Therapies Lead at Traumatic Stress Wales.
[C6] – Letter from the President of the UK Psychological Trauma Society, and Head of Research at Combat Stress, a specialist treatment centre for veterans.
[C7] – Letter from a clinical psychologist at Uppsala University Hospital, Sweden.
[C8] – Letter from the Consultant Clinical Psychologist at the Department of Psychotraumatology at Clinic St. Irmingard, Germany.
[C9] – Letter from a member of staff at the National Centre for PTSD Division of Dissemination and Training, at the US Department of Veteran Affairs, and a Clinical Professor at Stanford University Department of Psychiatry and Behavioural Sciences.
[C10] – Letter from the Lead Clinician for the Traumatic Stress Service (Cardiff and Vale University Health Board).
[C11] – Letter from the former Support Manager for the International Medical Corps, one of the world’s largest humanitarian first responder organisations.
[C12] – ITQ free online link
https://www.traumameasuresglobal.com/