

Final report

# **Eva Cyhlarova and Martin Knapp**



# For further details, please contact:

### **Martin Knapp**

Personal Social Services Research Unit London School of Economics & Political Science Houghton Street London WC2A 2AE Email: M.Knapp@lse.ac.uk

www.piru.ac.uk



Final report

**Eva Cyhlarova and Martin Knapp** 

Personal Social Services Research Unit, London School of Economics and Political Science



# **Funding**

This report is based on independent research commissioned and funded by the NIHR Policy Research Programme via its core support for the Policy Innovation Research Unit. The views expressed in the publication are those of the authors and are not necessarily those of the NHS, the NIHR, the Department of Health and Social Care, 'arms' length bodies or other government departments.

#### **Acknowledgement**

We would like to acknowledge with thanks Dr Nika Fuchkan who conducted the literature review and Dr Madeleine Stevens who carried out the cost analysis for the project. We are enormously grateful to all people who took part in the evaluation.



Contents	Executive summary     1.1 Background	1
	1.2 Aims	1
	1.3 Methods	1
	1.4 Results	1
	1.4.1 Numbers of people in each stage of the Programme	1
	1.4.2 Client interview and questionnaire responses	2
	1.4.3 Outcome measure results	2
	1.4.4 Costs associated with exposure to the attacks	2
	1.4.5 Interviews with professionals	3
	1.5 Conclusions	3
	1.6 Recommendations	3
	2. Background	5
	2.1 Literature review	5
	2.2 The affected UK population	8
	2.3 The UK mental health response programmes	8
	2.3.1 The Screen and Treat Programme in England	8
	2.3.2 The Screen and Assess Programme in Scotland	9
	2.3.3 Veterans NHS Wales	9
	3. Aims of the evaluation	10
	4. Screened and treated population	11
	5. Clients' experiences of the Programme	14
	5.1 Method	14
	5.1.1 Ethical approval	14
	5.1.2 Design	14
	5.1.3 Recruitment of participants	14
	5.1.4 Participants	15
	5.1.5 Materials	15
	5.1.6 Procedure	17
	5.2 Analysis	17
	5.3 Results	18
	<b>5.3.1</b> Characteristics of responders	18
	5.3.2 Responders' participation in the Programme	18
	5.4 Interview and questionnaire responses	19
	<b>5.4.1</b> Onset of mental health problems	19
	5.4.2 Impact of the attacks on daily life	19
	5.4.3 Impact on work, studies, and daily activities	22
	<b>5.4.4</b> Use of support services since the terrorist incident	23
	5.4.5 Impact of treatment on work or study	26
	<b>5.4.6</b> Clients' suggestions for improvement	28
	5.5 Outcome measure results	30
	5.6 Costs associated with exposure to the attacks	30
	5.7 Pen pictures	35



6.	y and property of the contract of the con	38
	6.1 The CYP population	38
	<b>6.2</b> Professionals' views of the Programme for CYP	38
	6.3 Clients' views of the Programme for CYP	38
	6.4 CAMHS experience	39
7.		40
	7.1 Method	40
	<b>7.1.1</b> Design	40
	7.1.2 Participants	40
	7.1.3 Materials	40
	7.1.4 Procedure	40
	7.2 Professionals' experiences of the Programme	41
	7.2.1 Screening	41
	7.2.2 Assessment	42
	7.2.3 Treatment	42
	7.3 Experiences of service providers	43
	7.3.1 Service providers sample	43
	<b>7.3.2</b> Support for service providers	43
	7.3.3 Challenges for the PRTE team	44
	7.4 Experiences of planning and administering the Programme	44
	7.4.1 Set-up phase and timing	44
	<b>7.4.2</b> Funding	45
	7.4.3 Data sharing	45
	7.4.4 Partnerships	46
	7.4.5 Management	46
	7.4.6 Planning future responses	46
8.	Study limitations	48
9.	Discussion	49
10	. Recommendations	51
11	. References	52
40	Annandias	<b>.</b> .
12	Appendices	54
	<ul><li>12.1 Appendix 1: Service use questionnaire</li><li>12.2 Appendix 2: Unit costs</li></ul>	54 56
	I C.C MUNCHUIX C. UTIIL GUOLO	מט



# 1. Executive summary

# 1.1 Background

The Screen and Treat Programme was set up by the Department of Health and Social Care¹ in March 2016 to support UK citizens affected by the terrorist attacks in Tunisia (March and June 2015), Paris (November 2015) and Brussels (March 2016). In Phase 1 of the Programme, packs including Public Health England (PHE) screening tools were sent to approximately 500 people whose contact details were known to the Metropolitan Police. The questionnaires screened for Post-Traumatic Stress Disorder (PTSD). Those people who screened positive were referred to the Psychological Response to Traumatic Events (PRTE) team at South London and Maudsley NHS Foundation Trust (SLaM) for telephone assessment (Phase 2). People assessed as being in need of treatment were referred to local services, via the Improving Access to Psychological Therapies (IAPT) programme, and were followed up until the end of their care pathway by PRTE staff.

#### **1.2** Aims

The original aims of this evaluation were: to record the numbers of people contacted and involved at each stage of the Screen and Treat Programme; to find out if the Programme has been effective in screening and referring people to appropriate services; to measure the Programme's economic impacts; to assess its acceptability to users and to understand how the agencies involved work together. A secondary aim was to find out how the Programme worked for children and young people under the age of 18 years.

This report describes the progress of people affected by the incidents through the stages of the Programme, their experiences of the Programme, their use of other support services, the costs of those services, and the experiences of professionals involved in setting up and administering the Programme.

## 1.3 Methods

In total, 529 people potentially affected by the Tunisia, Paris and Brussels terrorist attacks and known to the Metropolitan Police were invited to take part in the evaluation. A total of 79 people (15%) responded; 77 completed a service use questionnaire and 36 were interviewed. Of those 529, twenty of the individuals who had completed their treatment under the Programme by September 2017 agreed to make available to the research team their pre-and post-treatment outcome measures. In addition, eleven representatives of agencies involved in planning and delivering the Programme were interviewed, as were five service providers who received multiple referrals via the Programme.

#### 1.4 Results

#### 1.4.1 Numbers of people in each stage of the Programme

Of the 529 people invited to take part in the Screen and Treat Programme, 195 returned screening questionnaires to PHE and 179 of them screened positive for PTSD. Of the 119 people that PRTE assessed, 78 (66%) reported significant symptoms and were offered treatment through the Programme (another 29 were already in treatment via another route). By September 2017, 34 individuals had completed treatment, 28 were still in treatment, three were waiting for treatment and 13 had withdrawn from treatment.

<sup>1</sup> The Department of Health was renamed the Department of Health and Social Care in January 2018. Although the evaluation of the Screen and Treat Programme was commissioned prior to this date, the current name is used throughout this report.



The Programme identified seven children and young people under the age of 18 years; all of those screened positive and three were referred for treatment (another three were not assessed as they were already in treatment, and one was not possible to contact). By September 2017, two had completed treatment, one was still in treatment, one had withdrawn and no information was available about the other two.

#### 1.4.2 Client interview and questionnaire responses

Most evaluation participants reported that the experience of the attack had a major impact on their lives; frequently occurring problems included anxiety, depression, difficulty going out and travelling, sleep problems, panic attacks, flashbacks and hyper-vigilance. Many people had found it hard to cope with work; about a third had to reduce their working hours and a similar proportion had taken sick leave.

Many participants took up help offered by charities and non-NHS organisations, with mixed experiences. About two thirds of participants had sought help from their GP prior to the Programme's launch. Many did not think their GP had been helpful. Several said their GPs had prescribed sleep and/or antidepressant medication, while only a few were referred on to a mental health professional and then usually did not find the treatment helpful.

For participants referred for treatment by PRTE, waiting times for treatment varied from no delay to a few months, but most participants found the treatment they received helpful and felt their health was improving as a result. By December 2016, four interviewees had completed treatment, ten were still in treatment, three were waiting for treatment to commence and one had withdrawn. The majority of interviewees thought that the Programme had started later than it should have and that there was not sufficient information available to them in general as well as about the Programme specifically.

#### 1.4.3 Outcome measure results

Twenty evaluation participants completed treatment and had available outcome measure scores by September 2017. Their mean scores were significantly better post-treatment compared to pre-treatment on all three scales: depression, anxiety and distress.

#### 1.4.4 Costs associated with exposure to the attacks

The service cost data analysis suggests that there are economic impacts of exposure to the attacks, including effects on work/study and participation in society. Some people received treatment that was not helpful, or was provided at the wrong time, indicating inefficient use of resources. Some people received treatment that was helpful and is likely to be cost-effective in the longer term.

- The biggest costs were hospital costs and costs for psychologists and therapists.
- Individuals whose symptoms had not improved had higher mean costs than those whose symptoms had improved.
- Individuals who did not take part in the Screen and Treat Programme reported higher mean costs than those who took part in the Programme.
- Mean costs were higher for female than for male participants.



#### 1.4.5 Interviews with professionals

Both PRTE and IAPT clinicians saw the outreach model as appropriate for identifying people at risk, and thought the central assessment, referral and coordination were important for both clients and local service providers. Clinicians working in local IAPT services valued the specialist training and supervision they received from PRTE.

Professionals found the set-up phase of the Programme difficult and mentioned a variety of reasons. For example, no budget was identified at first, multiple organisations were involved and no data-sharing agreements were in place. The latter complicated the communication with people affected throughout the Programme's duration. These issues caused a significant delay in the start of the Programme, which was seen as the main limitation to its effectiveness.

For future mental health responses, it was thought that there should be a budget in place as soon as possible after the event, an agreed protocol with defined responsibilities and information-sharing agreements; the service should be built into NHS structures and processes, and GPs and existing non-NHS organisations should be utilised. The 'watchful waiting' period should last one to three months and timely and effective treatment should be offered.

#### 1.5 Conclusions

The terrorist attacks in Tunisia, Paris and Brussels had a profound impact on the lives of those who were present or affected indirectly. Adults who took part in the Screen and Treat Programme in England were satisfied with the treatment they received, although they thought it would have been more helpful if it had been available sooner after the events. Clinicians valued the training and supervision provided by central team.

The small sample who completed outcome measures reported significant improvements in their symptoms of depression, anxiety and distress.

It was evident that costs of involvement in the attacks went beyond the costs of services used, with additional economic impacts on work, productivity while at work and participation in non-work activities.

Funding and data-sharing between agencies were the main barriers to timely contact with the affected individuals, causing a delay in the start of the Programme. Self-referral and GP identification of PTSD and referral to appropriate care were not effective, suggesting that people potentially affected by similar incidents need to be supported to access effective and timely treatment.

# 1.6 Recommendations

From the information gathered in this study, we would recommend that the Department of Health and Social Care:

- Ensure there is a system in place that would enable immediate response to terrorist attacks, building on the experience of previous responses and on NICE guidance.
- Define and agree roles and responsibilities of all government and non-government agencies involved.



- Develop guidelines for collection and management of contact details of all affected people, including options for how those details would be collected under various incident scenarios (e.g. in the UK or abroad, large numbers affected in one location or spread across the country).
- Appoint an organisation responsible for setting up a register of people affected as soon as possible after an incident.
- Arrange data-sharing agreements between the relevant agencies, within the constraints of the Data Protection Act, to facilitate direct communication with people affected.
- Prepare a plan for informing and communicating with people affected by terrorist incidents, including how internet and other means would be utilised; e.g. develop and publicise an accessible website with information about symptoms of trauma, PTSD, depression, anxiety and other potential problems, self-care, support available and how to access mental health services.
- Ensure that GPs and other health professionals are adequately trained to identify PTSD and other mental health problems to make appropriate referrals to evidencebased treatments.
- Utilise existing networks of IAPT services and services provided by non-NHS organisations to provide timely evidence-based advice, support and treatment.
- Develop guidance for approaching problems likely to be encountered when implementing a mental health response (e.g. assessing mental health needs, coordinating an appropriate response, ensuring equality of access to care).
- Consider a systematic approach for identifying children and young people in need of support.



# 2. Background

## 2.1 Literature review

Terrorist attacks are increasingly frequent global phenomena with wide-reaching behavioural, health and economic consequences. Post-traumatic stress disorder (PTSD) is often cited in the literature as one of the most common consequences of exposure to terrorism and indeed one of the most frequently documented (Neria et al., 2008; DiMaggio & Galea, 2007; Boscarino, 2002). About 30% to 40% of people who experience a terrorist attack are likely to have PTSD two years later (Whalley and Brewin, 2007; Brewin et al., 2010).

PTSD is often unnoticed by individuals themselves and by primary and secondary care professionals, and common mental health problems might also be missed. Self-referral and the subsequent use of routine medical care appear to be very low, leading to persistent unmet mental health needs and potentially high costs. Early detection and treatment of PTSD are important in order to avoid it becoming a chronic condition with potentially profound consequences.

Apart from PTSD, both directly and indirectly exposed victims are at risk of developing other mental health problems, such as major depressive disorder, panic disorder, general anxiety disorder, agoraphobia, travel phobia and substance abuse disorder (although the risks are lower for indirectly exposed individuals). Significant psychological, social and economic effects of terrorism on both directly and indirectly exposed individuals and their families, and on society as a whole, are well documented. These effects make it important to address the needs of all exposed individuals in immediate, medium-term and long-term phases of psychosocial response.

Our literature review<sup>2</sup> reported below identified seven articles covering post-disaster psychosocial support and mental health services<sup>3</sup>, and confirmed what is already known about psychosocial responses.

Mental health response constitutes an important part of the general emergency response plan and it should take into account and respond to the diverse and changing nature of needs and characteristics of the exposed individuals on their pathway to recovery (NIMH, 2002). A systematic review of mental health response to community disasters concluded that 'a systematic framework of case identification (distinguishing between normative emotional distress and psychopathology), triage, referral to appropriate services, clinical assessment and provision of evidence-based mental health interventions should be integrated into emergency medicine and trauma response' (North & Pfefferbaum, 2013).

However, identification and treatment of the longer-term mental health outcomes has traditionally not been incorporated into emergency response policies. There is limited experience with establishing an effective mental health response for individuals who develop PTSD or common mental health problems following an attack. Furthermore, there is little evidence on the processes of setting up and managing a mental health response programme, including the programme's acceptability to potential users, the length of the programme and its content.

As outlined above, some people affected by terrorist incidents recover on their own; however, a potentially large proportion of people may need to be supported to access timely and effective treatment. To date, several guidelines have been developed outlining the principles for evidence-based approaches of providing mental health support and treatment for people affected by terrorist attacks. Examples of guidance

- 2 In the review, we included peerreviewed English-language literature on disaster mental health response in PsychlNFO, PubMed, Google Scholar, and Cochrane database of Systematic Reviews. The focus was on original research and systematic reviews.
- 3 Two articles covering psychological first aid (one systematic literature review and a commentary on current evidence), one covering post-disaster psychosocial support, one systematic review on mental health response to community disasters, one review on mental health services after disasters, one article covering international perspective and lessons learned from psychosocial responses to disaster and mass-trauma, and a study on early psychosocial interventions in Europe.



for the mental health response to major incidents include the NATO model of Psychosocial care for people affected by disasters and major incidents (NATO, 2009), The European Network for Traumatic Stress (TENTS) project (TENTS guidelines, 2009), and also the NHS Emergency Planning Guidance (2009), which draws on the NATO and EU documents.

Guidelines for psychosocial response highlight the need for multilevel support strategies in response to the needs and circumstances of affected individuals (Reifels et al., 2013, Bisson et al., 2010). These interventions include provision of practical help, community-based interventions, low-level support, specialised and intensive mental health treatment such as trauma-focused cognitive behavioural therapy (CBT), and eye movement desensitization and reprocessing (EMDR) (Reifels et al., 2013). Some of the key lessons about psychosocial responses to disaster and mass trauma are based on anecdotal evidence from international disaster experts which included: 'tailoring psychosocial disaster responses to the specific disaster, provision of multidimensional care, targeting at-risk population groups, proactively addressing barriers in access to care, recognising the social dimensions and sources of resilience, efficient coordination and integration of disaster response services, integrating research into disaster response planning' (Reifels et al., 2013). On a European level, there is a consensus on early psychosocial care, but many of the guideline recommendations are not implemented in practice (Te Brake et al., 2009; Te Brake and Duckers 2013).

The importance of integrating a psychosocial element into a general emergency response has been recognised and was, for example, implemented in the mental health response after the 2005 London bombings (Brewin et al., 2010). There is divided opinion about whether screening for mental health problems after a major incident is the most effective way of identifying individuals with symptoms, as the sensitivity and specificity of screening has not been established (Williams et al., 2010; Bisson et al., 2010). However, it has been suggested that systematic screening offers a good pathway into care for symptomatic individuals and results in a greater number of referrals than the standard referral channels, as was the case of the approach after the 2005 London bombings (North and Pfefferbaum, 2009). NICE also recommends considering screening of 'all individuals after a major incident' (2005).

The results of research on the London bombings suggest that outreach and screening, with referral to treatment, may be an effective way of identifying individuals with mental health needs (Brewin et al., 2010). Similarly, a study of the national outreach strategy after the attacks in Norway in 2011 showed that 87% of participants received 'proactive outreach.' Here each municipality appointed a designated contact person who monitored survivors' needs for at least a year, provided screening at regular intervals and links with primary care and mental health services, if needed (Dyb et al., 2014). The approach was similar to the current Screen and Treat Programme as it also used screening and relied on local services, but organising this in each municipality – without a centralised screening team – had the advantage of local knowledge of services.

An innovative approach to identify populations at risk during and soon after disaster by using social media (Twitter) was explored in a study by Gruebner et al. (2016). The authors believed that emotional reactions extracted by automated sentiment analysis of the data are predictive of long-term mental health needs and provide useful insights for provision of mental health services (Gruebner et al., 2016).



Available evidence from the evaluation of the NHS Trauma Response Programme implemented after the 2005 London bombings suggests a high level of client satisfaction with the programme. However, the issue of data-sharing was of particular concern to the programme funders and implementers as well as first-response agencies, and presented a significant hurdle in the setting-up of the programme (Traumatic Stress Clinic, 2008; Brewin et al., 2009). Many participants reported that they were expecting the NHS services to be in touch and did not mind being contacted (Brewin et al., 2009).

The key lessons and recommendations identified by the London bombings mental health response team were (Traumatic Stress Clinic, 2008):

- 1. Standardise emergency planning. Establish a strategic emergency plan based on the NHS response experience, which standardises interagency emergency procedures and contains templates of action, contacts and referral pathways for future crisis events.
- **2. Secure funding.** In order to have the necessary expertise and core processes available for future crisis, secured, ring-fenced crisis funding is critical.
- 3. Formalise interagency collaboration. The networks and interagency partnerships established as part of the NHS response should be actively maintained: regular meetings, cross-functional projects and interagency training would optimise information flow, broaden links to other initiatives and enhance future crisis response.
- **4. Engage GPs more thoroughly.** More GP-focused training and communication is required to promote understanding of Post Traumatic Stress Disorder (PTSD) and of the services available within the stakeholder network.

McFarlane & Williams (2012) highlighted a need for creating awareness among health funders and planners about the immediate, medium-term and (in particular) long-term psychological and mental health needs of affected individuals. However, the lessons learned and the evaluation of the London bombings mental health response pointed out the lack of GP referrals and the lack of GP awareness of available services and even a lack of recognition of the mental health effects of trauma exposure and PTSD (Brewin et al, 2009; TSC, 2008). These findings are relevant in particular in the context of the GP being the only/main source of the referral pathway into the treatment.

In addition, evaluation of the mental health response programme after the London bombings emphasised the important role of local third sector organisations which provided mental health response services in the immediate aftermath of the events and in the longer term.

Finally, the findings of the Evaluation of the NHS Trauma Response Programme after the London bombings suggest that the programme was successful in identifying participants with greater mental health needs and providing them with treatment. It is not clear, however, whether the resources needed for screening and referral of people into existing services avert higher societal costs (Fuchkan, 2015).

Generally, there is limited evidence on the processes of setting up and managing a mental health response programme, including the programme's acceptability to potential users.



# 2.2 The affected UK population

On 18 March 2015, gunmen attacked the Bardo National Museum in Tunis, Tunisia. Twenty-two people, mostly European tourists, were killed, among them one British national.

On 26 June 2015, a terrorist gunman attacked tourists at a resort near Sousse, Tunisia. Thirty of the 38 dead and 15 of the injured were British citizens. Many more British holiday-makers were in the vicinity of the attack or witnessed it. The travel agency Thomson Holidays flew 2,500 British people back to the UK. It has not been possible to estimate reliably the number of people who were affected by the attack. Lists of holiday-makers from the relevant travel agencies operating in Tunisia were not available due to the absence of data-sharing arrangements. As British tourists returned to the UK, the Metropolitan Police gathered information on approximately 2,000 people and compiled a shortlist of individuals who could have been traumatised, had seen something significant or who could assist the criminal investigation or the coronial process. The police estimated that a total of 567 people could have been affected, including the next of kin of the 30 people who were killed and of the 15 people who were seriously injured.

Six terrorist attacks occurred in a number of locations across Paris on 13 November 2015. One British citizen was killed. The number of attack locations across the city made it more difficult for police to collect the details of all British citizens involved. Details of 57 British people were compiled by the police.

On 22 March 2016, three terrorist attacks occurred in Brussels. One British citizen was killed, four people were injured and several others witnessed the attacks.

# 2.3 The UK mental health response programmes

There were three separate mental health response programmes to the attacks: in England, Scotland and Wales.

# 2.3.1 The Screen and Treat Programme in England

The Screen and Treat Programme in England (set up by the Department of Health and Social Care; DHSC) was designed to support UK citizens affected by the terrorist attacks in Tunisia (March and June 2015), Paris (November 2015) and Brussels (March 2016). The Programme ran from March 2016 to March 2017. Some people were still continuing with their treatment with their local mental health services beyond this date. This became an England-only programme.

All eligible people (defined as the 'witness population') who were known to the Metropolitan Police or the Foreign and Commonwealth Office (FCO) were invited to take part in the Programme. These were identified as injured, bereaved or witnesses. In Phase 1, a screening questionnaire was sent out by the Metropolitan Police to each individual or family involved on behalf of Public Health England (PHE). Responders who screened positive for PTSD (the 'screen-positive population') were referred to a DHSC-commissioned Psychological Response to Traumatic Events (PRTE) team at South London and Maudsley NHS Foundation Trust (SLaM) for telephone assessment (Phase 2). People who were assessed as being in need of treatment (the 'treatment population') were referred by PRTE to their local mental health services



such as the NHS Improving Access to Psychological Therapies (IAPT) programme, or NHS secondary care services, and were followed up by the PRTE team until the end of their care pathways or the end of the PRTE contract. For children and young people under the age of 18 (CYP), the assessment was conducted face-to-face at six regional hubs and, if needed, CYP were referred to NHS Child and Adolescent Mental Health Services (CAMHS). The majority of the treatment elements of the Programme were provided via existing NHS services.

People who did not reply to the Phase 1 screening invitation, or whose screening was negative, were sent a second invitation for screening six months later.

At the time of this study, details about information, assistance and support services available for victims, witnesses, family members and all those affected by terrorist attacks in the UK were available on the Home Office website.<sup>4</sup>

#### 2.3.2 The Screen and Assess Programme in Scotland

During the early months (September to December 2015) of the planning of the Programme by DHSC, Scottish residents were included in the response, and the plan was for their details and their completed assessments to be shared with the Rivers Centre in NHS Lothian, who would facilitate access to treatment in NHS mental health services in Scotland. However, in January 2016, the Rivers Centre wanted to prioritise the assessment of children and offer face-to-face assessment to both children and adults. The Scottish Government therefore decided to opt out of the DHSC plan and to coordinate a parallel but separate Screen and Assess Programme in Scotland. There were 18 Scots identified by screening as experiencing psychological distress and 15 were referred for treatment.

#### 2.3.3 Veterans NHS Wales

The Welsh Assembly, with support from the Cardiff and Vale Traumatic Stress Service, set up an outpatient programme for Welsh nationals affected by the Sousse attack. The existing Veterans' NHS Wales service was utilised, which provides psychological therapies for ex-military personnel across Wales. This service was able to provide treatment quickly and locally: it was in operation within two weeks of the attack. The service operates a 'hub and spoke' model, with the hub in Cardiff overseeing the delivery of the service and the 'spokes' covering all six of the Welsh Health Boards. Fourteen people were referred to the service and 12 were referred to treatment; pre- and post-treatment outcome measures suggested that over 70% of individuals showed clinically significant improvement.



# 3. Aims of the evaluation

The aims of the evaluation described in this report are as follows:

- to find out if England's Screen and Treat Programme was effective in screening and referring people to appropriate services;
- to find out if people recovered;
- to measure the Programme's economic impacts;
- to test the Programme's acceptability to users;
- to understand how all the agencies involved work together.

The evaluation of this Programme is based on adult services because the numbers of children and young people (CYP) were very small and the screening and treatment pathways were different. Therefore, with the agreement of the DHSC and other parties, CYP were not included in the evaluation as participants. However, a secondary aim of our evaluation was also to gather information about the system and processes for CYP through the qualitative interviews we conducted with their parents and with professionals involved in the Programme.

In this report, we present the following results:

- the progress of people affected by the incidents through the stages of the Programme;
- service use of the affected people;
- costs of services used by the affected people;
- individuals' experiences of the Programme;
- analysis of treatment outcomes data available by September 2017 (N=20);
- inter-agency working and the experiences of professionals, including service providers, involved in setting up and administering of the Programme.

We use the term 'client' to refer to people who witnessed or were affected by the terrorist events to avoid confusion with other individuals included in this study (such as professionals and civil servants), although we recognise that the term is not quite right; we have not been able to think of a better term.



# 4. Screened and treated population

In total, 483 individuals and a further 49 families affected by the attacks were sent information about the Screen and Treat Programme with a questionnaire screening for PTSD (see Figure 1). In total, 195 valid questionnaires were returned to PHE and 179 (92%) of these people screened positive. It is not known whether or not the non-responders to the PHE invitation received psychological treatment elsewhere, nor is it known whether the prevalence of PTSD was similar in the non-responders.

Figure 1 shows how individuals who screened positive for PTSD at the PHE screening stage progressed through the assessment and treatment stages of the Programme. Of the 119 people that PRTE assessed, 78 (66%) reported significant symptoms and were offered treatment (40% of returned questionnaires). By September 2017, 34 individuals had completed treatment, 28 were still in treatment, three were waiting for treatment to start and 13 had withdrawn from treatment. There were another 22 people who were not assessed by PRTE, but were still followed up and supported by PRTE. Of those, 13 had completed treatment, eight were still in treatment and one was waiting for treatment.

An additional 29 people (15% of returned questionnaires) did not progress beyond the screening or assessment stages because they were already in treatment that they had accessed via another route.

PRTE estimated that the Programme reached four times as many people as standard care would have achieved, and it successfully engaged older people, a particular 'at risk' group.

<sup>5</sup> The total numbers of completers/ still in treatment or waiting do not add up to the number of people referred, as PRTE still provided follow-up and support for people who were not assessed by PRTE. However, PRTE still recorded and reported their progress through treatment, but they were not included in the total number of referrals as they were not directly referred by PRTE.



Figure 1 Numbers screened, referred and treated (by September 2017)

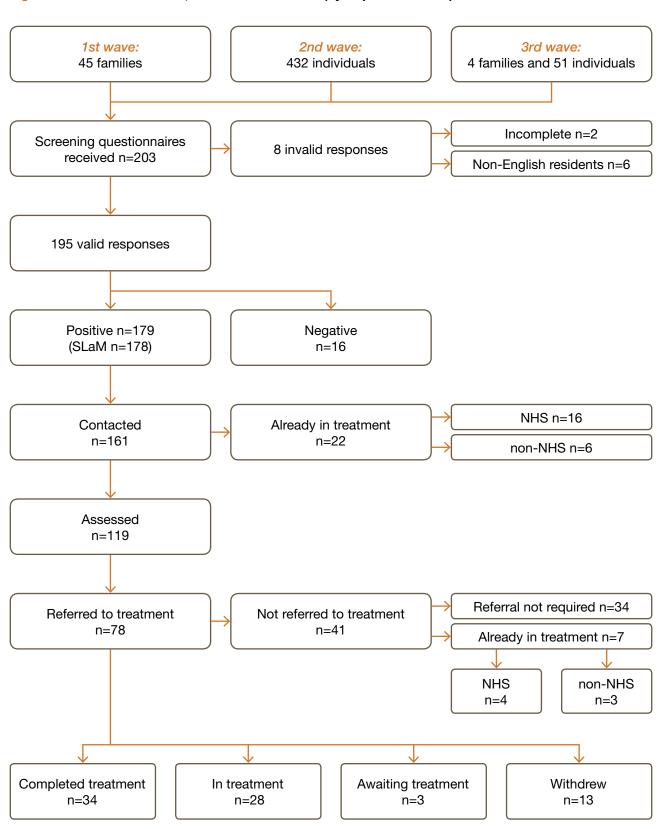




Table 1 shows the main diagnoses associated with clients' referrals to local services; two thirds had a diagnosis of PTSD and 36% of depression and anxiety.

Table 1 Main diagnoses of people referred

Main diagnosis	N	%
Adults		
PTSD	73	61%
Depression	4	3%
Depression and Anxiety	42	36%
Depression and Anxiety and Alcohol abuse	1	1%
Children		
Trauma	3	

Table 2 shows how long people waited for treatment appointments: 78% were seen within 18 weeks of referral but 14% waited for their first appointment for longer than 18 weeks. (Also, some people chose to wait, e.g. until after the memorial.)

**Table 2 Waiting times for appointment** 

Waiting time	N	%
Within 6 weeks	30	39%
Between 6-18 weeks	31	39%
In excess of 18 weeks	11	14%
Still waiting for first appointment	5	7%



# 5. Clients' experiences of the Programme

#### 5.1 Method

#### 5.1.1 Ethical approval

The Health Research Authority (HRA) classified this project as a service evaluation and therefore not requiring NHS Research Ethics Committee (REC) review and NHS R&D approvals. Although this was a low-risk study, we sought approval from the LSE REC to ensure that any potential ethical issues had been appropriately addressed.

#### 5.1.2 Design

This part of the evaluation followed a mixed-methods design, collecting both quantitative and qualitative data using both one-to-one interviews and a postal questionnaire.

#### 5.1.3 Recruitment of participants

Between September and November 2016, 529 adults from the witness population were invited to take part in the evaluation. Most (476) had been in Tunisia, 41 in Paris and 12 in Brussels. Seventeen people had opted out of the evaluation at previous contact with PHE and therefore were not sent the invitation. Potential participants were sent a letter, via the Department of Health and Social Care (contact details were held by the police – the DHSC did not have access to these data), with an information sheet about the study, a consent form and a questionnaire. (The LSE research team was not given the names or addresses of any such individuals.) Potential participants were invited to participate in the research in the following ways:

- (a) by allowing the research team to access data already collected about them by the services involved in the Programme, and/or
- (b) by completing a questionnaire, and/or
- (c) by completing an interview.

In each mailing, four copies of the materials were sent so that other people in the households who may not have been known to the police could also return a questionnaire if appropriate.

A reminder was sent to those who did not reply after 4-5 weeks.

Members of the witness population consented to taking part in the evaluation by returning a signed consent form (and if they chose, also the completed questionnaire) in a stamped pre-addressed envelope. People who had consented to being interviewed were contacted by the research team and an interview was arranged, either over the telephone or face-to-face.



#### 5.1.4 Participants

Table 3 shows the numbers of people who completed each of the three elements of the evaluation and their participation in the Programme.

Table 3 Number of participants in each evaluation element (as of March 2017)

Evaluation element	N total	N took part in Programme	N did not take part	N did not indicate
Questionnaire	77	49	22	8
Interview	36	28	8	_
Pre-and post-treatment outcomes data	20	20	_	_

#### **Questionnaire participants**

Seventy-seven people from the witness population returned a usable questionnaire. The majority (71%) were female and 29% were male. Responders' ages ranged between 19 and 76 and the mean age was 56 years. The majority (91%) had been affected by the incidents that took place in Tunisia in June, while three had been involved in the Paris attacks, two in the Brussels incident, and two did not state in which attack they had been involved.

#### Interview participants

Fifty-one people indicated they would be willing to be interviewed. Thirty-six of those completed an interview (three face-to-face and 33 over the telephone); six could not be reached, five were in contact initially but contact was lost and four did not want to take part any more when they were approached.

The interview sample comprises only 7% (n=36) of the known witness population (n= 546). It was not possible to increase this number due to several limitations, such as indirect access to potential participants (whose identities we were not permitted to know until they contacted us) and a limited number of responders to the interview invitation. Therefore it is important to bear in mind that the participants' views may not be representative of the known witness population or of the (unknown) whole population affected by the terrorist incidents.

#### **Treatment outcomes participants**

In total, 39 people on the PRTE database consented to sharing data already collected about them by other agencies. Pre- and post-treatment outcome measures were available for twenty people who had completed treatment by September 2017.

### 5.1.5 Materials

#### Questionnaire

A modified version of the Client Service Receipt Inventory (CSRI; Beecham & Knapp, 1992) was used to assess individual-specific service use associated with the events. The CSRI was also utilised in research on the Screen and Treat response to the 2005 London bombings (Fuchkan, 2015). Two supplementary questions asked about the impact of the event on the responder's work, studies, family responsibilities, leisure or other activities. The questionnaire is shown in Appendix 1.



#### **Interviews**

The interview topic guides were informed by (i) NICE Guidance on PTSD (NICE guidance [CG26] 2005); (ii) previous studies (e.g. Brewin et al., 2008, 2009, 2010; Fuchkan, 2015); and (iii) consultation with PTSD experts and an expert by experience (Dr Alison Beck, Dr Jelena Watkins). Summaries of interview topics are shown in Table 4.

#### Table 4 Interview topics for people affected by the attacks

#### All individuals affected by the attacks

- how participants heard about/were contacted by the Programme
- if they would have contacted their GP or mental health services if they had not heard about the Programme
- how they felt about the screening process
- the impact of the event on their life (health, social etc.)
- their health status from after the event until first contact with the Programme
- current health status
- what would improve their experience of the Programme
- the experiences of participants' children, if they were affected

#### Participants referred for assessment/treatment

- how they felt about referral to SLaM
- how they felt about the assessment process
- timing
- experience/satisfaction with their treatment options
- timing of changes in thoughts, feelings and behaviour
- timing of realisation something was wrong
- what would have helped notice something was wrong or access help
- what worked well and what did not

#### People who did not engage in the Programme/who dropped out/did not take up referral

- reasons for not using the service/dropping out etc.
- current health status
- what would make a difference to their engagement with the Programme

#### **Outcome measures**

Individual outcomes data were collected by PRTE at the assessment stage and at end-of-treatment for each client who was for referred for treatment. The measures included in this data set are widely used, validated instruments:

- The Patient Health Questionnaire (PHQ-9, Kroenke & Spitzer, 2002) is used to monitor
  the severity of depression and response to treatment. The scale comprises nine items
  which are rated on a 4-point scale ranging from 0 (not at all) to 3 (nearly every day).
- The Generalized Anxiety Disorder scale (GAD-7; Spitzer et al., 2006) is used as a screening tool and severity measure for generalised anxiety disorder. The seven items are scored as 0 (not at all) to 3 (nearly every day).
- The Revised Impact of Event Scale (IES-R; Weiss & Marmar, 1997) measures subjective distress caused by a traumatic event. It includes 22 questions in three subscales: Intrusion, Avoidance and Hyper-arousal. The responses are rated on a 5-point scale ranging from 0 (not at all) to 4 (extremely).



Initially, we planned to utilise the Work & Social Adjustment Scale (WSAS, Mundt et al., 2002) in the evaluation, but it was not possible to include the scale in the final outcome measures, as IAPT services did not report WSAS scores.

#### 5.1.6 Procedure

Responders who consented to taking part in an interview were contacted by the research team and an interview was arranged, either over the telephone or face-to-face. Most participants (33) chose to be interviewed over the telephone.

Participants indicated on the consent form if they agreed to share data already collected by other services with the research team. Pre- and post-treatment outcome measure scores were supplied to the research team by PRTE.

## 5.2 Analysis

#### **Analysis of questionnaire data**

Data were analysed using SPSS 22. A chi-squared test was used to examine the associations between participation in the Programme and the following variables: age, gender and work or study activities.

# **Analysis of interview data**

Based on issues identified in previous research (King, 2012), an initial analysis framework was created for qualitative data. Six client transcripts were analysed using this template and additional categories were created as new topics emerged, resulting in a revised analysis framework. The rest of the data were analysed using the revised framework and any new topics were noted.

#### **Analysis of treatment outcomes data**

Changes in health status and other characteristics of participants over time were used to assess the effectiveness of the Programme. A paired samples t-test was used to determine changes in depression, anxiety and subjective distress from baseline to end-of-treatment. Twenty evaluation participants had completed their treatment by September 2017 and agreed to make available their pre-and post-treatment data.

#### **Analysis of cost data**

The following costs were calculated using questionnaire and interview data:

- mean costs by each service category, total costs and total mental health costs;
- mean total costs and mental health costs by change in depression and anxiety symptoms;
- mean total costs and mental health costs by participation in the Programme;
- mean total costs and mental health costs by gender;
- impact on productivity and intangible costs were also explored.

Unit costs for each service category were taken from PSSRU Unit Costs of Health and Social Care 2016, NHS reference costs 2015–16 or Fuchkan (2015), adjusted for inflation where necessary (see Appendix 2).



#### 5.3 Results

In the following section, we report the combined results of the interviews and questionnaire data.

#### 5.3.1 Characteristics of responders

#### **Characteristics of questionnaire responders**

The majority of responders to the questionnaire (71%) were female and 29% were male. Responders' ages ranged between 19 and 76 and the mean age was 56 years. As shown in Table 5, the majority (91%) had been affected by the incidents that took place in Tunisia in June, while three had been involved in the Paris attacks, two in the Brussels incident, and two did not state which attack they had been involved in.

Table 5 Number of participants by incident

Incident	N	%
Brussels	2	2.6%
Paris	3	3.9%
Tunisia	70	90.9%
Unknown	2	2.6%

A minority of responders (7%) said that young people (aged 18 or younger) in their household had also been affected by the incident. In most cases, it is not possible to determine from these data whether the children were present when the incident took place or were affected indirectly by the impact of the incident on other household members.

#### **Characteristics of interview responders**

The majority of the people interviewed were female (27 of 36). Their mean age was 58 years, ranging between 29 and 72 years. All identified themselves as White British. Thirty-three had been affected by the incident that took place in Tunisia in June, one by the Paris attacks and two by the Brussels incident. Two interviewees said that a young person was affected by the incident.

#### 5.3.2 Responders' participation in the Programme

Data on participation in the Programme were available for 71 responders. Of those, approximately two thirds (68%) had taken part in the Programme, while one third (32%) had not taken part.

To compare age groups, responders were divided into approximately equal groups of younger people (aged 19 to 59) and older people (aged 60+). Table 6 shows that the proportion of younger people who took part in the Programme was greater than the proportion of older people: most of the younger responders (86%) took part, while only half (50%) of older people took part. A chi-squared test indicates that this association between age and participation is significant:  $\chi^2$  (1,68)=10.3, p=0.02 (2-sided).



Table 6 Participation in the Programme by age

Age in years	Took part in th	Totals	
	No	Yes	
10.50	5	31	36
19-59	14%	86%	100%
	16	16	32
60+	50%	50%	100%
Tetale	21	47	68
Totals	30%	69%	100%

Gender did not have a statistically significant association with participation in the Programme. Men and women were equally likely to have taken part in the Programme:  $\chi^2$  (1,69)=0.9 (p>0.05).

Of the 36 interview participants, 28 had taken part in the Programme and eight had not taken part.

#### 5.4 Interview and questionnaire responses

#### 5.4.1 Onset of mental health problems

Twelve of the interviewees (n=36) responded to a question about timing of changes in their thoughts, feelings or behaviour since the attacks. Seven realised they were experiencing mental health problems immediately after the incident and therefore sought help early on. Four people reported a delay in symptoms coming on and a lack of awareness of their problems. Their reports of delayed onset varied from a few days to a few weeks.

The impact took about three weeks to come out. After we got home we weren't too bad, but after 10 days we noticed the changes, thoughts, we couldn't watch TV, then it started building up.

[Three months later] in a restaurant I had an extreme startle response (to party poppers). I was hiding under the table. It took me days to calm down. Then the episodes increased.

#### 5.4.2 Impact of the attacks on daily life

Interviewees and questionnaire responders were asked to describe how their lives had been affected by their experiences of the terrorist attacks. Most of the interviewees (31 of 36) reported that the experience of the terrorist incident had a major and extensive impact on their lives. Several responders said that their experience of the attack had affected every aspect of their lives. Very few were able to get on with their lives as before.

My whole world was tipped upside down, it affected every part of my life.

Anxiety was among the most frequently-reported problems, and seven responders also reported panic attacks. Many questionnaire responders reported feeling a generalised sense of anxiety, or being in a state of constant hyper-vigilance.



Interviewees described a range of typical PTSD symptoms (re-experiencing symptoms, avoidance, hyper-vigilance).

#### Difficulty going out or being in public

Thirteen questionnaire responders and 14 interviewees said that their anxiety was particularly acute in crowded or busy places, and many therefore avoided such places if possible. Several people said that they were afraid to go out.

I avoid busy places, enclosed areas, hotels, trains, shopping centres, cinemas, theatres, tourist attractions

Most journeys undertaken are exhausting because I am constantly on high alert, very selective where and when I go anywhere.

Twelve questionnaire responders and ten interviewees said that they now found loud noises and bangs, especially fireworks, very upsetting.

#### Difficulty travelling and going on holiday

Six questionnaire responders found travel difficult, particularly air travel, and some found it difficult to go on holiday.

Travel has been a hard thing to do. It's taken a year to get on a plane, to go to another country. Not totally confident even now.

Those who had been affected by the beach attack in Tunisia found going to a beach particularly difficult.

#### Sleep problems, nightmares and flashbacks

Several questionnaire responders, including five interviewees, reported sleep disturbances or nightmares, or both. Flashbacks were mentioned by several responders, including five interviewees.

I get flashbacks about what I saw in Tunisia on the beach.

#### **Depression**

Many reported low mood, depression, or a lack of motivation.

I can't be bothered, have no inclination to do anything or go anywhere.

Associated with anxiety and depression, several reported that they now had difficulty concentrating.

I cannot read a book or listen to music as I used to.

Social isolation was a problem for several responders.

I have opted out of a normally active social life.

Feeling that unless they were there, others can't understand.

#### **Bereavement**

Some responders had been on holiday with friends or relatives who had been killed in the attack.

I lost three family members in the Tunisia beach attack. I find it very difficult to accept the way they died. I live day to day and I find life very angry, I don't bother with people, only family. I find it hard to accept our loss.



Since mum and dad were murdered, nothing will be the same again.

In addition to bereavement, some people also had financial concerns.

Loss of income has impacted on all the above, lost financial security and loving husband, unable to return to my role at work. Just returning long term phased plan with different responsibilities.

#### Relationships

Several responders had experienced relationship difficulties since the attack.

The event has caused a lot of tension between family members.

I argue with [my] husband, distance myself from family members for fear of dying.

#### **Disability**

Physical injuries sustained in the attacks had left some disabled.

I have been left disabled by the injuries I received in the terrorist attack.

Initially discharged from hospital, unable to do housework, cannot leave house unless in wheelchair.

#### **Physical ill-health**

Four interviewees reported significant deterioration in their physical health as a result of the attack. (None of these were injured.) Two people mentioned their multiple sclerosis getting worse, one chronic obstructive pulmonary disease, one heart issue; one of these people is about to become disabled as a result of the physical health problem. Other health issues, such as asthma and minor foot injuries, were also mentioned but did not cause major problems.

#### **Prejudices**

Some found that they had developed new or increased prejudices towards people who appeared to be Muslim.

[I am afraid of] people of similar ethnicity dressed in black.

I have distrust/hate for certain groups of people.

#### **Preoccupations**

A few people spent a lot of time thinking about how close they had come to being killed in the attack.

I think about it almost every day and realise how lucky myself and my family were. I am still finding it hard to believe I am still alive.

# Mild reactions

Only five people said that the experience of the event had a relatively limited impact on their lives. However, some of them still had to manage minor issues relating to the experience.

I learned to live with it, tried to get on with my life as soon as possible, shut the door on it. It will never go away. The news brings it back. We lost two friends, but we still got to live, you can't let things like this dictate you.



#### 5.4.3 Impact on work, studies, and daily activities

Questionnaire participants were asked about the impact of their experience of the terrorist attack on their normal activities. Table 7 shows that just over a third (36%) had needed to reduce their working or studying hours; a similar proportion (37%) had taken sick leave and 12% had become unemployed or had ended or interrupted their studies. More than two-thirds (68%) reported that other daily activities, such as housework and family responsibilities had been affected.

Table 7 Impact on work or studies

Did these things happen as a direct result of the terrorist attack?	% reporting a negative impact	Total N responding
Had to reduce working or studying hours	36%	56
Taken sick leave	37%	62
Unemployment, studies ended or interrupted	12%	60
Other daily activities been affected	68%	65

Prior to the incidents, 28 of the 36 interviewed people were in regular work, six were retired, and two were not working. Following the attacks, thirteen people took time off work, ranging between two weeks and ten months. Two of the retired people thought that they would have taken time off work if they had been working as they could not concentrate on work. For most interviewees, the impact of the events on their working lives was very significant. One felt unable to cope with work and had resigned and another had to move back to a family home because of financial difficulties due to time off work.

I have been off work [the last ten months]. My stress bucket is filled up by the trauma, more stress from life under normal circumstances is ok, but I can't deal with it now. It changed my life, I am having to move because of financial reasons, I'm moving back home.

There were a few who did not take time off work, as they found it harder being at home with time to think about their experiences than being at work.

Since the incidents, one person resigned from her job, one chose to take early retirement, one is unable to work and two will not return to work because they are caring for their partners who were severely affected by the incident. As of December 2016, some people were still working reduced hours and/or their sickness days were higher than previously.

I had [surgery] in July and was signed off work till October. I was very anxious about what had happened, but it took my mind off it for a bit, but when I had to go back to work I could not do it, I had to resign.

In the end I had four months off work. I was not able to function, then I had a phased return to work. It took all year.



#### 5.4.4 Use of support services since the terrorist incident

The interviewees described a range of attitudes regarding coping with the impact of the event and looking for help and support. Six participants thought they would get over it without the need for professional support.

I didn't go to the GP to get help, I sat at home and vegetated, thinking time is a healer, wasn't happy to go to the supermarket. I did as little as I needed with going out, I did lock myself away, I felt safe, I thought I would get over it on my own.

Table 8 shows that nearly two thirds of questionnaire responders (64%) had seen their own GP as a result of the terrorist event, and approximately the same proportion (63%) had seen an NHS psychologist or counsellor. Just over half (52%) had seen a private therapist. Fewer (18%) had seen a nurse, had been to a hospital Accident and Emergency department (12%) or had seen an NHS psychiatrist (10%).

Table 8 Use of support services as a result of the terrorist event

Have you used these services as a direct result of the terrorist event?	%	Total N responding
GP	64%	73
NHS psychologist or counsellor	63%	73
Private Therapist	52%	61
A nurse	18%	65
A&E	12%	68
NHS psychiatrist	10%	60

Table 9 shows the number of services used by responders. Most responders (82%) had used at least one of the services previously listed in Table 8. The mean number of services used by responders is 2.1 (median=2).

Table 9 Number of services used as a result of the terrorist event

Number of services used as a direct result of the terrorist event	N	%
0	14	18.2
1	15	19.5
2	27	35.1
3	9	11.7
4	1	1.3
5	5	6.5
6	4	5.2
7	2	2.6
Total	77	100



#### Frequency of using services

For some of the services used, the numbers of participants who used services are too few to compute a meaningful average number of contacts. Furthermore, the range of responses (1 to 100) is too great to compute a reliable mean. The median number of contacts with each service is shown in table 10 with the most frequently-contacted at the top of the table. This does not include responders who had not used the service at all (i.e. whose number of contacts is 0).

Table 10 Median number of contacts with each support service for those using the service

Support service	Median	Minimum	Maximum	N
NHS psychologist or counsellor	8.0	1	65	35
NHS psychiatrist	7.5	2	16	4
Private therapist	5.0	1	21	21
Nurse	3.0	1	100	9
A&E	2.0	1	11	7
GP	2.0	1	21	36

#### Relationship between use of GP services and use of other services

As might be expected, for services that are normally accessed through a GP, responders were more likely to have seen their GP. Of the responders who had seen an NHS psychologist or counsellor, four fifths (79%) had also seen their GP, while a fifth had not seen their GP. Similarly, all of those who saw a nurse or an NHS psychiatrist had also seen their GP. It is interesting that this was also true for services that are not normally accessed through a GP: three quarters (75%) of the responders who saw a private therapist had seen their GP, and all of the eight people who attended Accident and Emergency departments had also seen their GP.

#### **Experiences with GPs**

Of the 36 people interviewed, 25 had sought help from their GP prior to the Programme's launch. Two people said that they did not or would not go to their GP; one thought she would get over it on her own, and another one was not sure what support he would need.

Of the 25 who had sought their GP's help, nine thought their GP was helpful or sympathetic.

The GP has been excellent. He didn't know what to say but has been very supportive.

Most did not think their GP had been helpful. GPs appeared more willing to deal with physical symptoms or injuries, for example, minor foot injury, heart issue, asthma. Thirteen people were prescribed sleeping pills and/or antidepressant medication. Only two people found that the medication helped them, most did not take it.

[My GP] was a bit shocked, she didn't say a lot and offered tablets... She didn't know what to tell me.



Eight people were referred by their GP to a mental health professional, for example, to a mental health nurse, community counselling or generic CBT. Most people reported that the treatment they received did not help them. Only one person found the generic CBT helpful and continued with it under PRTE's supervision once the Programme was underway.

I went to the GP, got sleeping pills and was sent to a nurse. She was not able to deal with it.

#### **Hospital admissions**

Six questionnaire responders (9%) said they had been admitted to hospital as a direct result of the terrorist incident. Of those, three were admitted once, two were admitted twice and one had three admissions. Four people reported how many days they had spent as a hospital inpatient, and their answers ranged between three days and 108 days. Of the three people who reported a reason for their admission, two were for gunshot wounds and one for angina.

#### **Outpatient attendances**

Fifteen people (31%) said they had been referred to a hospital as an outpatient as a direct result of the terrorist incident. The number of outpatient appointments that individuals had ranged between 1 and 50. The reasons given for the first appointment include "PTSD" (5 people), "CBT, EMDR" (1), "heart surgery" (1), "shrapnel pain in legs" (1), "unstable angina" (1), gunshot injuries (1), "I was present during the attacks, my husband was killed", "trauma practitioner".

#### Support from the travel agent

Fourteen interviewees and one questionnaire respondent took up counselling provided by the travel agent Thomson Holidays fairly soon after their return to the UK. This usually consisted of a few sessions face-to-face or over the telephone. Some people thought it was good to have someone to talk to after returning home, but mostly it did not help in dealing with the consequences of the experience (e.g. "the counsellor cared but couldn't help"). These sessions helped some people to realise that they were not well, were getting worse, needed time off work or more help.

I got counselling from Thomson... but then went back to work and was hiding in the office.

#### Other types of professional seen by participants as a result of the terrorist event

A third of questionnaire responders (33%) had seen another type of professional. Of those who specified the type of other professional, five had seen someone from the Victim Support charity; three had had therapy sessions with Nik and Eva Speakman, who appear regularly on ITV's *This Morning* programme; two said that their employers had offered professional help; one received treatment from Assist Trauma Care; one had called the Samaritans.

Six interviewees highly praised the Foundation for Peace/Survivors' Assistance Network for informing and supporting them to get to the appropriate help. Victim Support was mentioned by three interviewees. They offered useful general guidance and support in one case, but provided community counselling in two cases and that was not seen as very useful. Three interviewees received support from Assist Trauma Care; two found the treatment helpful, one did not. Several people used the Facebook group set up by one of the survivors as a support group and found it very helpful. In addition, therapy provided by Nik and Eva Speakman was also mentioned and group sessions are still being organised.



Assist Trauma Care have been really good, the counselling has helped, we would be lost without it.

The most helpful were the Foundation for Peace who got the ball rolling. ...It was well over a year before I got some help, somebody from the Warrington Foundation for Peace wrote a letter to the GP and got some further help.

Eventually I went to a group session with the Speakmans; I found it really helpful and thought I would be fine, but got worse after about a week.

#### 5.4.5 Impact of treatment on work or study

Of the 55 people who responded to the survey question "Did treatment for PTSD or other mental health issues related to the event help you to stay in work/study, or to return to work/study earlier than you otherwise might have done?", just under a quarter (24%, 13 people) thought that their treatment had helped them to stay in work or study or return to it earlier.

#### **Effect of Screen and Treat Programme**

The proportion of people who reported that their treatment had helped them stay in or get back to work or study earlier was higher for those who had taken part in the Programme than for those who had not. Of those who had taken part in the Programme, nearly a third (32%) reported that their treatment had a positive impact on their work or study activities. For those who had not had taken part in the Programme, only one person (6%) had found their treatment useful in this regard. A chi-squared test confirms the statistical significance of the difference is:  $X^2$  (1,50)=4.1, p<.05 (one-sided test).

Table 11 Cross-tabulation of impact of treatment and participation in the Programme

Did treatment for mental health issues help you to stay in/	Took part in the Programme		Totals
return to work/study earlier?	No	Yes	
Me	15	23	38
No -	94%	68%	76%
Voc	1	11	12
Yes	6%	32%	24%
Tatala	16	34	50
Totals	100%	100%	100%

#### Client interviewees' experiences of the Screen and Treat Programme

Interviewees found out about the Programme in different ways; fourteen were informed about the Programme by letter (many were not sure if it came from DHSC or FCO), eight found out at a meeting (probably organised by FCO), four from the police, one from Facebook and one from personal communication; six people were not sure how they heard about it and two were not aware of the Programme.

The Foreign Office sent communications, I didn't fill it in straight away, I didn't know how relevant it was, but as time went on I thought it may be useful. I didn't go looking for it.



I was tempted not to go to London, I was so anxious, but then the Talking Therapies came out of it. But if I had not gone to [a meeting], I don't think I would have been told about it.

#### Screening and assessment

Interviewees thought the screening and assessment was well organised and did not mind that the clinical assessment was conducted over the telephone. The PRTE psychologist team was consistently highly praised. After assessment and referral, the team kept in regular contact with clients, provided care coordination with local services, supported people while waiting for treatment and intervened in cases of slow response or issues arising with local services.

I had excellent support from them.

The support provided to those who did not need referral any further was also seen as valuable.

[The psychologist] was very supportive. [They] rang back on a monthly basis, to check how things are progressing. She also spoke to the lady who is doing EMDR.

#### Waiting times for treatment

Waiting times for treatment varied considerably for the 18 people referred via the Programme. Four people reported no delay and a further three people appeared satisfied with the timing; one person who withdrew did not say. Ten people had to wait a few weeks to several months. Three participants said that PRTE had to intervene and put pressure on local services as they were not getting treatment even after a few months' wait.

From me being referred, I spent four months waiting for an appointment. That was the hardest, it did a lot of mental harm, a year has passed..... even though I was getting support [from SLaM], but I needed treatment.

[The local service] took a long time to respond: three to four months, then after the initial interview, four or five months passed before any treatment, and that was with pressure from [SLaM].

#### Impact of treatment

Overall, the 28 interviewees who took part in the Programme were satisfied with the support they received. Eighteen participants were referred for treatment and ten did not progress beyond the screening stage. Of those, five were already in treatment elsewhere, three did not need referral, and two declined referral. One of those thought talking to her partner was sufficient and one felt too upset to see a therapist and had found previous therapy through her GP unhelpful.

Of the 18 people referred to NHS treatment via the Programme, 13 were referred for CBT and two for EMDR; three were waiting for treatment to start. By the time of their interview for this research project (November 2016 to January 2017), four people out of 18 had completed treatment, ten were still in treatment and one had withdrawn. (The five people who had already been in treatment by the time of the screening were also still in treatment at the time of their interview.)

#### Treatment results

Each of the 18 people who took up treatment via the Programme reported getting worse prior to starting the treatment. As a result of the Programme, eleven felt they were getting better, one felt the same as before, two were not sure if it was helping,



one did not find the treatment helpful and withdrew after four or five sessions; three were still waiting for treatment to start.

At the time of their interview, four people had completed treatment and were managing well, even though they were still dealing with some symptoms.

I am pushing myself to do things now. I have to get on with my life. I am always looking over my shoulder. I do struggle with the Tube, but I've got to get on with it, life is not going to be the same.

I'm feeling better, I don't cry as much. I have flashbacks but not as much, and can control them.

Eight of the ten people who were still in treatment at the time of their interview were finding the treatment helpful. These included two participants who were dissatisfied with some issues in the early stages of their treatment and asked PRTE to intervene. In addition, one person was not sure if her treatment was helping and another one had only just started treatment and could not say.

I see the positive effect of the therapy, definitely, it's good to go to someone who is qualified to say that it is normal.

I am getting better but still not right, I can go to the gym now, but I don't like driving and being around people. I used to be sociable.

Many participants felt their mental health was improving, even though they still had to manage symptoms which were limiting their lives.

It is getting better, but I am worrying all the time that something is going to happen again, even if I know the chances are slim. We are never going to be the same people as before, but that is something I can't accept. It had a huge impact.

I am almost recovered, almost as normal as before; that would have not happened without Screen and Treat.

## 5.4.6 Clients' suggestions for improvement

#### **Timing of the Programme**

Of the 36 people who were interviewed, 28 accessed the Programme. Of those, 26 expressed views about the timing of the Programme. Twenty-one participants thought the Programme had started too late.

I found it [the Programme] good, but the timing was out, really out, I could have done with it earlier.

Also, four of the eight people who did not take part in the Programme thought that help should have been available sooner.

The longer it went on, it made matters worse, you can't move on until you have been through some sort of treatment.. it would have been better sooner that we got help.

Many felt that if they had access to support earlier, they would have improved earlier, and that their health had deteriorated before they received treatment.

Everybody thought that if they had been contacted sooner, they would have received help sooner and it would have been better sooner, a lot less stressful.



[By the time the Programme was available] it was too late, I had already decided I couldn't cope with that job. I couldn't go back to work at the end of October. This [the Programme] started in April; shame it was too late.

However, the timing worked well for five people.

I didn't feel like talking for a while.

A related issue to timing was the finding that people may not ask or look for help, even if they will take it if it is offered. Several people indicated that earlier information about available support would have encouraged them to pursue it and possibly improve their health earlier.

... Had I received the info earlier, it would have prompted me to do something earlier... I didn't realise how affected I was until other things started to piled up.

It wasn't until I got the referral from government offering help... Some people don't always ask for help... it would be good to have some information available. I was worried that I would be sectioned, how severe it was... People don't realise that it is a normal reaction, you don't need a straightjacket.

#### Information and communication

Improving information and communication was also a frequent suggestion. People did not mind being contacted, but of the 28 people who engaged with the Programme, ten reported lack of information about available help (although many also felt overwhelmed by the amount of correspondence they received).

The whole process you felt like you have been in the dark, that you are not cared about, that you are not important.

We had so many letters, I guess I must have been aware. I didn't want to know, was trying to deal with it myself. I had several phone messages, I can't even remember, I always said no.

Six interviewees said that the Facebook group set up by one of the survivors was their only source of information. (Several participants described the police set-up web page as difficult to use.) Some participants were aware of the data protection issues which prevented the agencies from sharing information and contacting people directly.

If I had not found out by accident, who knows how long it would have taken, that was frustrating more than the event itself.

They relied on people speaking to the Met on arrival, but some bypassed it, they just wanted to get home.... When I asked why wasn't there a list from the tour operator, [the MP] said "we cannot do that because of data protection". Surely there must be a way to override this, it was a lame excuse.

Eight of the 36 interviewed people did not engage in the Programme; four of those also expressed frustration about the lack of information about support and two were not aware of the Programme.

If it wasn't for the Facebook page we weren't able to find any information. We were scraping around for support, didn't know what was there.

Four people were positive about the information and communication they received, although sometimes they were not sure which agency was being in contact.



[There was] a lot of communication which was excellent about the support, what was happening and when. I could not break down who it was from, but I was impressed with the information we were handed, and felt reassured.

#### **Therapist access**

Interviewees thought that access to appropriate therapists would be an important element of future responses. Although people were generally satisfied with their therapists, two had doubts about their therapist's experience in dealing with their type of distress, and in two other cases, PRTE helped to resolve issues related to therapists. In addition, one person did not take up treatment because previous therapy did not help.

There was a delay in getting to the right person. I could have been somewhere else by now.

#### 5.5 Outcome measure results

#### Changes in depression, anxiety and distress scores following treatment

Twenty participants who completed NHS treatment and had available outcome measure scores by September 2017 were included in the analysis. Table 12 shows that the mean scores on all three scales were significantly better post-treatment compared to pre-treatment. However, the number of completers was small and the lack of control group means that we do not know whether this improvement would have happened without the treatment.

Table 12 Comparison of pre- and post-treatment scores (mean and standard deviation [SD])

Scale	Mean (SD) pre treatment	Mean (SD) post treatment	N	t	Sig. (2-tailed)
PHQ-9 (depression)	12.8 (5.8)	4.8 (4.7)	20	7.84	<.001
GAD-7 (anxiety)	10.3 (6.1)	4.5 (4.1)	20	4.89	<.001
IES-R (distress)	49.6 (23.3)	16.7 (17.8)	20	7.00	<.001

#### 5.6 Costs associated with exposure to the attacks

Overall, the data on costs of services used suggests that there are both direct and indirect economic impacts associated with exposure to the attacks, including effects on work or study and participation in society. Some people received treatment that was not helpful, or was provided at the wrong time, indicating inefficient use of resources. Some people received treatment that was helpful and may be cost-effective in the longer term, although we are not able to evaluate those longer-term impacts in this study.

#### Costs by services category

As can be seen in Table 13, the highest cost elements other than hospital costs were for psychologists and therapists.



Table 13 Summary statistics by cost category

Cost category	N using	Mean per person cost (£)	SD (£)	Median cost	Max cost	Total cost across sample (£)
GP	51	127	160	72	756	6480
A&E	8	380	471	207	1518	3036
Nurse	12	469	1213	65	4300	5633
NHS psychiatrist	7	808	786	552	2208	5658
NHS psychologist	48	394	564	235	3055	18894
Private therapist	32	346	385	158	1659	11060
Other	15	121	152	47	440	1814
Inpatient*	5	3393	2341	2900	5800	16964
Outpatient	18	1125	1579	675	6750	20250
Total costs (including those reporting no services)	80	1122	2592	359	20135	89789
Outpatient mental health-related (component of Outpatient costs above)	10	1229	650	1283	2295	12285
Total 'Mental Health Costs' (excludes A&E and hospital costs related to physical health)	80	773	1325	301	7585	61824

<sup>\*</sup> We used inpatient long stay unit cost per stay for inpatient costs over one day. Some of these were much longer stays so actual costs will be higher.

The final row of the Table 13 excludes hospital costs related to physical injuries (where known). This total includes all service costs, including GP, but excludes A&E, inpatient stays (which participant comments suggest are all related to physical health), and outpatient contacts, where these were for physical health but *including* outpatient contacts for mental health. This will be referred to below as 'mental health costs' (MH costs), although it also includes all GP contacts.

#### Costs by change in depression and anxiety

As may be expected, those whose symptoms did not improve had higher costs than those whose symptoms have improved, but it needs to be emphasised that the subsamples were very small.

Scores at each time-point were coded by recognised thresholds for depression (PHQ-9) into not depressed, mild, moderate, moderately severe and severe depression, and for anxiety (GAD-7) into no anxiety, mild, moderate or severe anxiety. In the tables below, change between the two symptoms data collection points is categorised as follows:

#### Change categories

- 'not depressed/anxious': no depression/anxiety at both time-points
- 'recovered': no depression/anxiety at follow-up where there had been depression/ anxiety previously
- 'improved': a lower category of problems at the second time-point, but not none
- 'not improved': no change in depression/anxiety



Table 14 shows the mean total costs for each change category, while Table 15 shows the mean MH costs (as defined above) by change category. A small number of participants used services but did not score above the cut-off for depression and/or anxiety.

Table 14 Mean total costs (£) and standard deviation (SD) of services used by participants in each symptom change category

	N	Mean total costs	SD
PHQ-9 change			
Not depressed	2	503	354
Recovered	11	860	686
Improved	6	502	642
Not improved	1	7683	_
GAD-7 change			
No anxiety	3	366	344
Recovered	9	841	633
Improved	4	881	950
Not improved	4	2243	3648

Table 15 Mean MH costs (£) and standard deviation (SD) of services used by participants in each symptom change category

	N	Mean total costs	SD
PHQ-9 change			
Not depressed	2	503	354
Recovered	11	792	712
Improved	6	502	354
Not improved	1	7545	_
GAD-7 change			
No anxiety	3	366	344
Recovered	9	758	665
Improved	4	881	950
Not improved	4	2208	3580

#### **Costs by Programme participation**

Individuals who did not take part in the Screen and Treat Programme appeared to have higher mean service costs than those who *did* take part in the Programme (Table 16). It is possible that those who had already needed and received treatment did not take part in the Screen and Treat Programme. Unfortunately, the date at which any treatment (as a result of the Programme) began was not available, therefore we do not know in which cases this treatment is included in questionnaire responses. It is possible that additional sessions received by Screen and Treat participants may have occurred at a later date.



Also, it is important to bear in mind that the set-up costs of the Screen and Treat Programme itself were not included in the analysis. These included payments by DHSC to both SLaM and PHE for their involvement; in addition, DHSC and NHSE staff committed time to the Programme. Some of these costs can be seen as investments that would carry over to support mental health responses to future terrorist or similar incidents.

Table 16 Service use costs (£) by participation in Screen and Treat Programme (mean, standard deviation [SD] and median)

Participation	N	Mean total costs	SD	Median
No	22	1524	2332	482
Yes	50	673	865	313
Missing	8	2831	7000	423
Total	80	1122	2592	359
Participation	N	Mean total costs	SD	Median
No	22	1020	1695	347
Yes	50	586	741	271
Missing	8	1262	2577	423
Total	80	773	1325	301

#### Costs by incident and by gender

Table 17 shows that mean costs were higher for female than for male participants. Unfortunately, outcome data were only available for three males, so it was not possible to compare costs and outcomes by gender.

Table 17 Service use costs (£) by gender (mean, standard deviation [SD] and median)

Participation	N	Mean total costs	SD	Median
Male	22	796	1306	291
Female	58	1246	2937	419
Total	80	1122	2592	359
Participation	N	Mean total costs	SD	Median
Male	22	539	730	291
Female	58	861	1486	313
Total	80	773	1325	301

Service use costs for the subsamples involved in each terrorist incident were not possible to include due to the low numbers in some subsamples.



#### Impact on productivity

Out of 26 participants responding to the question about impact on work or study, 16 said they *had* taken time off work or study as a result of experiencing the terrorist attack, while ten *had not*. Table 18 shows that over a third (38%) had needed to reduce their working or studying hours; a similar proportion had taken sick leave and 11% had become unemployed or had ended or interrupted their studies. Questionnaire participants were asked about the impact of their experience of the attack on their normal activities. More than two-thirds (69%) reported that other daily activities, such as housework and family responsibilities, had been affected. Table 19 shows time taken off work reported by participants. Fourteen of those who had taken time off work gave information on their jobs which is shown in Table 20.

Table 18 Impact on work or studies

Effects on work/study as direct result of experience of terrorist attack	N reporting	%	Total N
Had to reduce working or studying hours	22	38	58
Taken sick leave	24	36	66
Unemployment, studies ended or interrupted	7	11	61
Treatment for mental health issues helped participant remain in/return to work or study	13	23	56
Other daily activities affected	46	69	67

**Table 19 Time taken off work** 

#### Time taken off work

- 10 months to date
- 2 weeks off, reduced hours for 6 months
- 2 weeks off, then changed duties
- 2.5 months
- 3 weeks
- 3 weeks off, now working 0.8FTE
- 4 months, resigned
- 4 months, then phased return
- 5 months
- 6 weeks
- a few days at a time, continues to take time off
- not worked since
- not worked since, become disabled
- reduced hours by 5hrs a week
- took early retirement

Table 20 Job information for those taking time off work as a result of their experience of the terrorist attacks

#### Job details

- DWP civil servant
- Business support role at county council
- Carer
- Carpenter
- Charity shop worker part time
- Construction driver
- Credit controller in a large office
- Holistic and sports therapist
- Mortgage advisor
- Police constable
- Psychologist
- Senior manager in a company
- Senior manager in banking
- University lecturer



#### Intangible effects

As shown in Table 18, 69% of those answering the question reported being affected by the attacks in other ways. These are likely to have intangible economic impacts such as reduced productivity while at work, and reduced participation in non-work activities. In some cases, there might also be knock-on career development implications. The interview data and pen pictures presented in this report illustrate this impact on individuals.

# 5.7 Pen pictures

Interview and questionnaire data were used to develop 'pen pictures' of three individuals to illustrate personal experience with support and services.

#### Person 1, in her early 50s, working in further education

This person was very upset by the incident. She was often alarmed by sudden noises, and certain triggers (such as similar events or helicopter sounds) caused her to panic. Shortly after returning to the UK, she received two counselling sessions arranged by the tour operator. The sessions helped her to realise that she needed time off work and psychological therapy.

She took a couple of weeks off work but felt that she needed to return to work and "get on with it". However, at work she found she was not coping and felt "exposed". One particular difficulty was that her employer required staff to undergo Prevent training aimed at enabling staff to spot signs of extremist radicalisation. Before the incident, she had completed the first half of the two-part course and, although she felt unable to do the second part, her employer insisted that it was compulsory. She said that she "crumbled".

Soon after the incident, she went to see her GP. She was very upset and found the consultation difficult, as "the GP felt uncomfortable and reacted the wrong way." The GP prescribed medication, which she found helpful. Later, she had to see another GP about sick leave and felt upset at the thought of having to tell the story of the incident again. She therefore asked if the other GP would read the previous GP's notes, and was relieved that they agreed, rather than requiring her to re-live her traumatic experiences.

Despite her effort to stay at work, she found that she had to take four months off because she felt unable to function. She then gradually returned to work. "It took 12 months of my life; I couldn't work because of what was going on in my head."

Since the incident, she has received many communications from various agencies. She found the information reassuring but could not work out the source of some of the communications. There were "lots of forms from different places" but she "filled in everything that came". Eventually – she was not sure when – she was contacted by the Screen and Treat Programme and sent back the completed screening form. As a result, about a year after the terrorist incident, she started her psychological therapy, which was continuing at the time of the interview for this study. During the few months' waiting time for her treatment, she found the regular telephone support by PRTE very helpful.

Initially, she had misgivings about psychological therapy. She had had face-to-face counselling in the past and had not found it useful so she thought she might have preferred telephone sessions. However, she did find the therapy useful, and was relieved to find out that, contrary to her expectations, they were not necessarily limited to 12 sessions so she did not feel she had to rush. She also thought the therapy had been offered at the right time: she would not have been able to cope if it had started sooner.



At the time of the interview, she had completed nine sessions of therapy and felt "very up and down but also a lot stronger" than before the start of treatment. She felt very much affected by the incident but was now more able to deal with triggers and similar events. "I hear it [loud noises and triggers] but I'm managing now. It's really hard to explain how it still affects you."

#### Person 2, in her 40s, working as financial advisor

Immediately after the incident this woman felt very anxious.

The first day we got back early in the morning, I took the dog out, I got half way around the field with my husband and I saw a man and had a panic attack that he was going to get my daughter.

The tour operator offered to provide counselling but this person did not ask them to come back after two visits. (They had to travel a long distance to reach her.) She received eight counselling sessions through work, which she found useful but they did not resolve her difficulties. The counsellor said she needed ongoing support and advised her to go to her GP. She had to wait a few weeks for a GP appointment. The GP was sympathetic and explained that it was best not to have any intervention for a few months and she accepted that it might be best to see how she got on. After a few weeks, she went back to her GP who referred her to a non-specialist NHS counsellor. She had to wait a few weeks again but eventually she saw the counsellor for twelve sessions. She said she did not find the sessions helpful; she did not have faith in the counsellor and, after a while, she became scared to attend the sessions because they left her feeling worse. The GP offered medication several times but she did not want to take it. "I wanted to be more alert. I was expecting another attack: that was the last thing I wanted."

She was entitled to take six months off work with full pay, but she thought work would take her mind off things so she only took two weeks off. However, when she returned, she did not feel able to face customers directly, so she found herself "hiding in the [back] office." Her employer offered her more sick leave, but she refused. She had a reduced workload and a different role for some time, so that she did not have to deal with the public. On reflection, she thinks she should have taken longer off work.

She was not sure what help she needed but, several months after the incident, she realised her health was deteriorating. She noticed her own distress in various actions, such as hiding things in the greenhouse "in case it happened again." She found out about the Speakmans from someone else who experienced the attack, and attended one of their group sessions. At first, she found it helpful and she thought she would be fine after that, but felt worse again after a week.

More than a year after the incident, her mental state had deteriorated more and she was feeling even worse. She was therefore pleased to receive a letter about the Screen and Treat Programme. As a result of the screening, she was referred to a specialist therapist, who she found to be very helpful. Nevertheless, she found filling forms at every therapy session difficult and thought that some people who are "too scared to admit it" may need additional support.

Therapists rely on the truth being noted; however, I censored or muted my answers because I was worried I would be sectioned and/or medicated if I answered certain questions truthfully.

She also thought that perhaps if she had seen the therapist straightaway, she would have found it easier to cope. She was discharged after about twelve sessions of specialist therapy and now feels that she is managing all right with family support.



#### Person 3, in her early 30s, working in local government

This person recognised her hyper-vigilance immediately after the attack. She was always on the alert and had extreme responses to sudden noises. "It took days to calm down." Soon after the incident, she actively sought support and saw her GP about her injuries. However, it was difficult for her to find accurate information about available services, and for her to obtain access to such services. She found it a very frustrating and difficult time; she felt that she was not being taken seriously and she had to put considerable effort into seeking out and requesting the services she needed. Since the incident, she has attended A&E once and seen her GP and mental health nurse multiple times. At an initial consultation with her GP, she discussed psychological support and was advised to contact her local IAPT herself, but was told that she would have to wait 20 weeks for her first appointment, which turned out to be the case.

She took three weeks off work for minor physical injuries. Her employer offered her a phased return to work but she found work a good distraction and therefore returned to work after three weeks, when she thought colleagues would be less inclined to focus attention on her experience, i.e. "once people had got over it". She received six counselling sessions arranged by her employer. She found it helpful to speak to someone about the incident early on.

During the 20-week wait for psychological therapy, she saw a mental health nurse working for the Survivors Assistance Network, whose assessment identified that she had PTSD and advised that she needed specialist psychological treatment as soon as possible. Unfortunately, there were no specialist therapists available in her county. The nurse identified such a service in a neighbouring county, and her GP agreed to refer her to it, but she needed to obtain the approval of her Clinical Commissioning Group (CCG) to fund the treatment. However, four months later, the CCG told her that they would not fund the treatment and that she should go through the local IAPT to see a Level 1 therapist. At this stage, she arranged a consultation and an assessment with a private psychologist.

After about 18 weeks, she started treatment at the local IAPT and found the sessions helpful. At the time the researcher interviewed her, she had attended ten sessions with a Level 1 therapist. She also attends monthly support group led by Assist Trauma Care (she travels three hours each way for group meetings).

During the waiting period, also through her own research, she found out about the Screen and Treat Programme but could not ascertain whether it would be available to people affected by the particular incident she had experienced because, at that time, it was specifically targeted at a previous terrorist incident. Eventually, she received the Screen and Treat Programme's screening questionnaire. Coincidentally, a few days after the sessions with the IAPT Level 1 therapist started, she received a call from PRTE to discuss her screening questionnaire. She forwarded a copy of her private psychological assessment to PRTE. PRTE noted that she was already receiving treatment and offered to provide specialist supervision to the therapist she was now seeing.

She noted that her partner also completed the Screen and Treat Programme's screening questionnaire at the same time as she, and he received a referral for therapy within a few days. As he had not been actively seeking support for a long time after the attack, his access to treatment seemed much quicker.

At the time of interview, she was working four days a week, taking off her treatment days. Her number of sickness days has increased since the time of the incident. "Some days it feels too much to get out of bed and come in." She felt that life would never be the same. "It is about learning to live with [the trauma] and understanding your limitations."

37



# 6. The Programme for children and young people

The Programme was also available to children and young people under the age of 18 years (CYP) with the difference that the assessment was done face-to-face at six regional hubs and, if assessed as in need of treatment, young people were referred to local child and adolescent mental health services (CAMHS).

CYP were not included in the evaluation as participants, but the secondary aim was to gather information about the processes for CYP through the qualitative interviews conducted with their parents and with professionals involved in the Programme.

# 6.1 The CYP population

The Programme identified seven children and young people under the age of 18 years; all of those screened positive and three were referred for treatment (another three were not assessed as they were already in treatment, and one was not possible to contact). By September 2017, two had completed treatment, one was still in treatment, one had withdrawn and no information was available about the other two.

# 6.2 Professionals' views of the Programme for CYP

Several of the interviewed professionals thought that the outreach to CYP was not successful, mainly because there were very few children identified, which was thought unlikely to reflect the numbers potentially affected. All of the few children screened scored positive for PTSD, which was seen as evidence that there were likely to be more children affected by the incidents who have not accessed screening.

Participants considered a number of reasons that may have contributed to this outcome; parents may not ask CYP to fill out the questionnaire if they do not think that they have problems, or they think they will find it upsetting. Also, it was implied that if parents did not have any post-traumatic issues themselves, it was not likely that children would have been screened.

The process of assessment and referral of CYP was straightforward to manage, mainly because there were so few young people identified. Some participants mentioned that the process of screening, assessment and treatment for CYP was initially unclear; however, it was resolved once the first child was identified and channelled through the system and a point of contact was identified.

When we had our first child, we didn't have the processes in place. Once we had the first one worked through and we knew who to contact, then it worked.

# 6.3 Clients' views of the Programme for CYP

Of the total of 79 responses to the evaluation invitation, six people (7%) indicated that CYP in their household were affected by the incident. Of those, two took part in the Programme and four did not indicate. It was not possible to determine from these data whether the children were present when the incident took place or have been affected indirectly by the impact of the incident on other household members.

Two adults who indicated that a young person was affected by the incident were interviewed. In one case the young person received treatment and the family member mentioned that "it worked OK". In the other case, the young person was having



multiple problems with their health and schooling, and the family was finding the situation very hard.

# 6.4 CAMHS experience

A representative of one CAMHS involved in treating CYP was interviewed, as shown in the Interagency working section below. As there was a waiting list of 4-5 months at the time, these individuals were prioritised and seen without delay. Two cases were referred to this service but only one took up treatment, which has continued for almost a year. By the time of screening, this young person was already being treated by their local CAMHS, even though there was a long waiting list. Coordinating two CAMHS providing different treatments was manageable but not easy. The trauma CBT specialist spent a lot of time liaising with the local team and also with the person's school, helping them understand how to support the young person.

In addition, it was logistically difficult to see the specialist CBT therapist, as it was a long way from the person's home, they had to take a day off school and the travel was expensive. It seemed that once the young person completed the CBT treatment, they would continue working with their local services, together with other family members.

The second young person was assessed but did not start treatment. The therapist spent some time liaising with local CAMHS, geographically closer, to see if this person could be prioritised as there was a three-month waiting list. It is not known if the young person was treated locally or not.

The therapist who assessed the two cases and treated one of them received a regular telephone supervision by PRTE which they found very helpful. The only criticism was that the therapist did not receive any information about the cases from PRTE.



# 7. Interagency working

# 7.1 Method

#### 7.1.1 Design

Representatives of relevant agencies were interviewed, including services involved in treatment delivery, to find out how they worked together, how the process worked, and any impact on services.

#### 7.1.2 Participants

The agencies involved in planning and delivering the Programme (DHSC, PHE, SLaM, NHS England and the Metropolitan Police) were invited to participate in the evaluation. The agencies recommended eleven representatives to be interviewed. In addition, twelve service providers who received multiple referrals via the Programme were invited to take part in the evaluation. These providers were recommended by PRTE and were a mixture of responsive services, services that were slower to respond and improved services. Representatives of four IAPT services and of one CAMHS completed the interview. All were clinicians in managerial roles and they had gathered information from other therapists who treated clients referred via PRTE.

#### 7.1.3 Materials

The interview topic guides were informed by (i) NICE Guidance on PTSD (NICE guidance [CG26] 2005); (ii) previous studies (e.g. Brewin et al. 2008, 2009, 2010; Fuchkan 2015); and (iii) consultation with PTSD experts and an expert by experience (Dr Alison Beck, Dr Jelena Watkins).

Summary of interview topics is shown in Table 21 below.

# Table 21 Summary of the interview topics for professionals involved in setting up and delivering the Programme

### Professionals (depending on role and involvement)

- role in the Programme
- presence of systems, sharing information
- timing issues, waiting times
- · treatment options, availability of suitable specialists
- any impact on local services
- management
- improvements needed, problems experienced and resolved
- views of the process for children and young people
- satisfaction

#### 7.1.4 Procedure

Representatives of the various agencies involved in setting up and delivering the Programme were invited to participate in an interview; fifteen were interviewed by telephone and one face-to-face.



# 7.2 Professionals' experiences of the Programme

Each of the professionals who were interviewed reported that the Programme worked well once it was set up and running. Participants thought the outreach model worked really well and that, without it, people would have missed the opportunity to receive appropriate care.

[People affected by these traumatic experiences] do not think of themselves as having mental health problems and that makes them reluctant to come forward.

Clinicians said that this group seemed to have a different set of needs from people who ordinarily present themselves for mental health care; their onset was acute and they saw themselves as people, not as having mental health problems. Many tried to "live with it", thinking it would go away. Some of those who tried to access care did not get to the appropriate treatment.

Now it's implemented, it works quite well, because it has been through the struggles of setting it up... Patients who may have not actively sought help on their own may access help which is important.

#### **GP** support

The interviewees reported that, even though patients had told their GPs that they had experienced a terrorist attack, GPs did not recognise PTSD symptoms. This is consistent with the clients' reports, as described in the Client interview results section above. One professional was surprised by GPs' lack of awareness.

My idea of a GP is naive - I would expect referral [to mental health services or IAPT] automatically when they hear the word 'terrorist'.

#### Other non-NHS support

This lack of suitable support meant that people looked for any help that was available. Several non-NHS organisations offered various kinds of help, but results were mixed. More details on the support that people accessed can be found in the Client interview results section. One clinician summarised it:

A lot of good things but also some that made me worried.

Professionals' opinions regarding the three stages of the Programme (screening, assessment and treatment) are described below.

#### 7.2.1 Screening

The screening phase of the Programme worked well and was delivered according to the agreed timescales. The screening was seen as "very good and efficient", and PHE passed information to the PRTE assessment team on a daily basis.

[The screening] worked fine within the external constraints. (We couldn't write to people... it makes it difficult to do anything.)

Some professionals questioned the value of the screening process, as almost all of the screenings returned a positive result. However, it was also noted that it would not be possible to get a clearer sense of the effectiveness of the screening without reaching all of the people affected by the events.



#### 7.2.2 Assessment

The central assessment and coordination of the Programme was provided by the DHSC-commissioned Psychological Response to Traumatic Events (PRTE) team at SLaM. It took some time to set up the service and to recruit and train staff, but the team received very positive feedback. Professionals from other organisations reported that the service worked well, and that it would have been difficult to coordinate the Programme without a central team.

The clinical assessments carried out by the PRTE team were described as very good and, after some initial short delays, very quick. As can be seen in the Client results section, clients found the assessments helpful, and the support and care coordination that the central team provided were "excellent".

In the case of families or groups of friends affected by the attacks, it was seen as important to be able to offer fairly equal treatment. The central team could coordinate their care and make sure that clients were assessed and treated around the same time and helped to avoid giving the impression that some were less deserving or "not worth it".

Navigating the process of referral was not always simple.

... although it is meant to be standardised across Trusts, it is not. It takes a lot of time to identify the point where to refer [clients] to.

Another issue that the PRTE team had to tackle was the wide variation in the type and level of support that clients received prior to the Programme's launch. As described in the Client results section, some people struggled to find help and some had tried anything available. In one case, the PRTE team saw a client who had found four different ways of accessing care. In this case, the PRTE team liaised with the other organisations to co-ordinate their care and ensure that the client received appropriate care.

#### 7.2.3 Treatment

Having a central team also seemed crucial for the treatment stage of the Programme, for both clients and also local service providers.

# **Support for clients**

The PRTE team stayed in regular contact with clients after referral, informed them if there was a waiting list for the services they were referred to, and provided support over the telephone during the period they were waiting for treatment. They acted as care coordinators and kept in contact with IAPT services and individual therapists. The team followed up clients until they finished treatment and helped them resolve any issues arising. This external scrutiny was useful for checking each individual's progress and for contacting them in case they fell out of treatment.

#### **Service providers**

All services (mostly Improving Access to Psychological Therapies; IAPT) contacted by the PRTE team were able to accept people for PTSD, and almost all of them (approximately 120) offered two types of treatment: trauma-focussed cognitive behavioural therapy (CBT) and eye movement desensitization and reprocessing (EMDR), while approximately five offered only one of those treatments. A few people were referred to Older Adult Services, but some had long waiting lists so it was considered more effective to refer them to IAPT.



There was considerable variability in waiting times among service providers. Some services were over-subscribed, with limited resources, which resulted in long waiting lists. Although the instruction from NHS England was not to prioritise the people affected by the attacks beyond the recommended waiting times, some IAPT services seemed to give them higher priority. Conversely, other services did not offer a treatment start date within the 18-week waiting target.<sup>6</sup>

There was also variation in quality as perceived by PRTE. Some services were thought to be run well, some less well. One professional mentioned that the communication to clients was misleading, as it implied that they were being offered a bespoke programme when in fact it was standard mental health care. However, once clients were receiving treatment, they generally found it to be very helpful. Further details can be found in the Client results section.

# 7.3 Experiences of service providers

#### 7.3.1 Service providers sample

The four IAPT services and one CAMHS who took part in the evaluation received 19 referrals of people affected by the attacks. Fourteen people were referred through PRTE, four by GPs and one had not sought help directly but was picked up by another person in their group. For the four IAPT services, average waiting times were reported to be 2-3 weeks, 4-5 weeks, 6 weeks and 25 weeks. In the case of the 25-week wait, clients coming via the Programme were prioritised and received treatment in about three weeks. One service had no mechanism for referral as people self-refer there, but PRTE ensured the clients reached the services without the need to self-refer as well. At the time of referral, the CAMHS had waiting times in the range of 4-5 months but the service prioritised the individuals referred by PRTE and they were seen without delay. On the whole, people from the Programme made up a very small proportion of the services' clients, so no significant impact on the services or their waiting lists was reported as a result of their treating these patients.

#### 7.3.2 Support for service providers

The PRTE team liaised with each local therapist who was allocated to treat one of their referred clients, providing a detailed handover and an assessment compatible with IAPT requirements. They also offered support, training and supervision to therapists. This specialist support was well received by therapists and uptake was higher than initially expected. One service suggested that this support may have had a general beneficial effect for IAPT services, which would have had a positive impact on other clients, not just those referred by PRTE. The IAPT clinicians thought that the Programme was a good way of ensuring that people did not fall out of the system. They also reported that their clients found the Programme very helpful.

Clinicians found the detailed assessments conducted by PRTE very useful and they felt reassured that they were done by a specialist team. They thought that the PRTE team provided good follow-up, made sure that people stayed engaged with the service provision, and provided clients with useful information and coping strategies.

The ongoing telephone support from the [PRTE] psychologist was incredibly helpful and it gave [the client] a good understanding of coping strategies, which helped our work.

6 The stated target is that 75% of new referrals to the IAPT programme should begin treatment within 6 weeks of referral, and 95% should begin treatment within 18 weeks (The Mandate: A mandate from the Government to NHS England: April 2015 to March 2016, p 16-17, available at: <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/486818/mndate-NHSE-15\_16.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/486818/mndate-NHSE-15\_16.pdf</a>).



Four of the interviewees reported that the therapists in their service received supervision by the PRTE team. The other manager was not sure if the therapists in their services took up the offer. It was noted by several therapists that being able to access specialist supervision was really useful. In particular a training session delivered to one of the services was seen as high quality and reassuring for IAPT staff.

#### 7.3.3 Challenges for the PRTE team

One clinician commented on the geographical challenge for the Programme as they thought that any team centrally-based would find it difficult to know what was available locally. It was also pointed out that to reconcile a centrally-run programme, access local services and offer equal provision is becoming increasingly difficult, as services are regularly reorganised and have increasing demand for their services and financial pressures.

One IAPT manager reported minor difficulties regarding communication between the IAPT, their clients and the PRTE team, which they thought was probably due to reduced capacity within the local IAPT service. However, this was viewed as part of the normal issues that arise "when two systems collide with each other". Also, the IAPT manager mentioned that the clinicians were initially defensive about receiving recommendations from PRTE. In the end, this service did receive training from PRTE and they were said to have found it reassuring to see that the specialist team followed similar processes to their established normal practice.

# 7.4 Experiences of planning and administering the Programme

#### 7.4.1 Set-up phase and timing

It was pointed out that as this was the first time since the 2012 NHS reforms that a mental health response programme had been set up following a terrorist attack, there were no protocols and no precedents on how to do it. Participants were not surprised by the "cumbersome" set-up phase of the Programme. Several people said that it takes time if a new programme is being set up, and that perhaps patients would receive a better service if it was embedded in the NHS.

Other factors contributing to difficulties in setting up the Programme included the number of agencies involved, negotiating contracts, clarifying responsibilities and getting a protocol finalised and agreed. It was said that a long time was spent on issues that could have been decided faster (e.g. how to contact people, which parts of UK would be included, terminology for personalised letters). To illustrate, it was mentioned that at least two or three months were spent on deciding how to contact people, but as there was no consent for sharing contact details across organisations, only the police could contact people directly.

All interviewed professionals thought the delay in setting up the Programme was a major limitation to its effectiveness. Furthermore, clinicians were concerned about the lack of timely and appropriate treatment and its consequences. People felt "isolated and not cared about", and one professional said "they had a year to get worse and develop bad ways of coping".

We were slow off the mark in terms of contacting people... People said they could have done with that six months earlier... it was a year after Tunisia.



#### 7.4.2 Funding

Planning and setting up the Programme were described as difficult, mainly because there was a commitment to deliver the Programme before the funding was in place. One interviewee said that "everybody thought that it was likely that there would be more attacks" but it was suggested that reluctance to acknowledge the possibility of future terrorist attacks had meant that was no budget had been allocated to supporting such people. It was therefore hard to plan before knowing the available budget.

The initial plans were ambitious and then got smaller, as we had no idea how much money we would have to pay people.

Another funding challenge was the difficulty of estimating the numbers of people who might be eligible to access the Programme, which in turn made it difficult to plan and contract a service.

It was difficult to know who to include as other attacks happened during the planning stage [Paris]".

It was also not known what proportion of eligible people would choose to access such a service.

It was an unknown quantity how many people will respond, which was difficult for planning. It could have been problematic if lots of people had responded.

There also appeared to be a fear among policy-makers of setting a precedent for funding the Programme, in case funds were not available in future.

#### 7.4.3 Data sharing

A lack of data-sharing agreements between the organisations involved contributed to delays in contacting people. Consequently, it was impossible for the organisations involved to contact and follow up people directly.

There was the unresolved issue of how we get the initial list of people, how we identify those at risk. Having a list of everyone exposed would have really helped and follow-up could have been managed better.

The professionals perceived a tension between privacy protection and mental health protection. There was pressure to contact all of the British people who were in Tunisia at the time of the attack, but it was not legally possible to acquire lists of such people from the travel agencies. Therefore, only those who identified themselves to the police upon their return to the UK could be contacted, and only via the Metropolitan Police. Therefore, some people who might have needed support would have been missed. Two people affected by the Sousse event confirmed that some of their fellow passengers bypassed the police at airports because they "just wanted to get home". (More details can be found in the Client interviews results section.)

The police responded to requests by other agencies involved by amending their initial approach when collecting information from people after the attacks. For example, they asked people returning to the UK to consent to sharing their contact details with other agencies; however, it was mentioned that it did not improve the data-sharing issue in practice. It was therefore an onerous task for the police to carry out all communications on behalf of all other agencies involved. This data-sharing problem was not a surprise to some of the professionals involved, as similar problems had arisen ten years previously, following the Indian Ocean tsunami and in 2005 after the London bombings.



#### 7.4.4 Partnerships

All the partner organisations involved in delivering the Programme were described as working well together, especially once the Programme was up and running. There were very positive comments that demonstrated how everybody worked hard to try to understand what was needed by the other organisations, for example, by making the process of referral from assessment to treatment fast and smooth.

There was some lack of clarity about roles and responsibilities to start with, but we ended up working well between the various organisations.

One professional mentioned that the relationship with academics involved in designing the screening tool was difficult at times, mainly because they were perceived as having too much influence on DHSC during the planning stage.

However, the professionalism of all involved was seen as "exemplary" and it was noted that many individuals put in more work than was warranted for a one-year project.

#### 7.4.5 Management

There were mixed views about the leadership and coordination of the Programme, attributed by some to the lack of familiarity with similar work, or by the view that a policy team is not best placed to manage a programme of this kind. In addition, DHSC was under pressure from FCO to deliver more than they thought was possible, perhaps because the legal distinction between DHSC and NHS was not always recognised by FCO. Although participants understood that it was a difficult position for DHSC to be in, they said it was quite difficult to work with [DHSC] at times" and that the internal politics and focus "could have been better".

One participant said that there was no clear sense of authority because nobody had committed to funding the Programme. It was also mentioned that there was no single individual who had experience with managing something like this before and that perhaps an external project manager would have helped. Nevertheless, there was also a positive comment about the management.

The people who were running it were accessible...they were responsive, taking advice if they have issues, very sensible.

Similarly, the Joint Officials Unit received mixed reviews regarding how well it was it was working. The Unit was seen as good at maintaining contact with all the organisations involved, even if there was frustration about the delay in getting the Programme up and running. One member of the Unit thought that it needed a more mature leadership to manage competing interests, as "some people focussed on delivery while others had a longer-term view".

#### 7.4.6 Planning future responses

Although it was recognised that the current response model may be expensive, it was thought that there should be a budget in place, an agreed protocol with defined responsibilities and information-sharing agreements. Several participants felt that in the future this kind of service should be built into the NHS, that it should be overseen by NHS England and that local services should be used (including GPs) to screen people



affected by terrorist attacks for PTSD. It was also mentioned that connecting people to GPs would be helpful in the long term, if terrorist incidents become more frequent.

The arrangement was right at the time as there wasn't a mechanism to do it in the NHS... it would help if it was embedded in the NHS.

The recommendations regarding timing were that one to three months of 'watchful waiting' and checking for symptoms would be appropriate, consistent with NICE guidelines which suggest screening and outreach in the first month after the incident. Several participants felt that a future programme should reach out to people early, give them a point of contact, help them normalise the experience, and provide them with information about "how to look after themselves".

Interviewees were aware that it may be hard to estimate the resources needed for responses to future incidents, as had been the case with the current Programme. Professionals were worried about large numbers coming forward and not about being able to respond to the need.

People were worried about huge numbers. We could start with something, a clinician and an admin, then can start judging the level of need and increase according to the need.

It was suggested that clinicians and CYP experts should be included early on in the planning of a mental health response. Clinicians recommended that a systematic screening of all CYP in identified families might be needed, to minimise reporting bias by parents. Non-NHS organisations that could be checked for quality standards were also seen as providing an opportunity to utilise existing resources in a future response.

Multiple ways of reaching out to people were recommended (e.g. website, blog), as was a range of interventions. For example, in the case of large numbers of people affected in the same area, group interventions as well as more intensive one-to-one interventions were recommended.

One IAPT manager suggested developing a network of trauma centres around the UK in preparation for coordinating a response programme if similar events occurred in future. Another IAPT manager reported a lack of a dedicated trauma service in the area and suggested that it would have been useful to be able to refer difficult and challenging cases to a national specialist centre, such as PRTE.



# 8. Study limitations

The main limitations of this study are related to the lack of information about the total population potentially affected by the incidents. Furthermore, the individuals who took part in the Programme – or indeed those who took part in the evaluation – may not be representative of the whole population affected, but we have no way of knowing. It is therefore not possible to represent the views of participants affected by the events as conclusive evidence. However, we believe that the study provides useful learning regarding participants' experiences of the Programme and also the experiences of the professionals involved in setting up and administering the Programme.

In addition, it was difficult to ascertain the effectiveness or economic consequences of the treatment provided to individuals, as only a small number of people had completed treatment (by September 2017) and thus only limited outcome data were available to us.



### 9. Discussion

The terrorist attacks in Tunisia, Paris and Brussels had understandably profound impacts on the lives of those who were present or affected indirectly. Most evaluation participants reported that their daily activities, working lives and general functioning were affected.

A large majority of those who returned screening questionnaires screened positive (92%), suggesting that unmet mental health needs were high many months after the incidents. This finding confirms previous reports of standard care pathways not providing the support needed by people affected by terrorist attacks (Brewin et al., 2009).

In Scotland, the programme followed the same approach with a similar delay in contacting people; a half of screening questionnaires returned by people affected by the Sousse attack screened positive (N=18; 15 people accepted treatment). On the other hand, in Wales, no screening was utilised but an outreach programme was established – with no delay – using existing expertise in traumatic stress service. 92% of people referred in Wales had significant PTSD symptoms, but the number of people was even smaller than in Scotland (12 out of 14 were offered treatment) and therefore it was possible to simply increase the existing service provision and offer treatment immediately.

The Welsh programme reported a high rate of PTSD compared to other studies, although this may have been the result of the rapid treatment provision. There is no consensus on the length of the 'watchful waiting' period after a major incident, but up to four weeks has been suggested by NICE (NICE guidance [CG26] 2005). It is possible that some people would have recovered without any intervention in the early stages, as has been shown previously (Kessler at al., 1995). Also, this response design did not allow for contact with people who did not experience symptoms. However, neither approach was able to identify the total population potentially affected by the attacks and therefore estimate the proportion of people with mental health problems as a result of the trauma.

In the present study, some people did not seek mental health support, but many of those who had seen their GP found that their GP did not offer an effective way of dealing with their symptoms. Medication was the first line of treatment offered by many GPs, even though there is limited evidence of its effectiveness in the treatment of PTSD (NICE guidance [CG26] 2005). Given the lack of appropriate support, the Screen and Treat Programme was perceived by participants as very valuable. They found the central screening and assessment team very helpful, especially the support provided during waiting times for local treatment.

The treatment options offered to adults who took part in the Screen and Treat Programme were trauma-focused CBT and EMDR, as recommended by NICE (NICE guidance [CG26] 2005). Participants were satisfied with the treatment they received, although they thought it would have been more helpful sooner after the events, possibly in line with the recommendation to provide treatment for acute problems within the first 3 months (NICE guidance [CG26] 2005).

The small client sample who completed outcome measures reported significant improvements in their symptoms of depression, anxiety and distress. However, the lack of control group means that we do not know whether this improvement would have happened without the treatment.

It was evident that costs of involvement in the attacks went beyond the costs of services used, with additional economic impacts on work, productivity while at work, and participation in non-work activities.



Funding and data-sharing between agencies were the main barriers to timely contact with the affected population, and to the start of the Programme. Data-sharing appears to be a recurrent issue in responses to major incidents, as found in the responses to the Indian Ocean tsunami and the 2005 London bombings (National Audit Office, 2006; Brewin et al., 2009). Self-referral and GP identification of PTSD and referral to appropriate care were not effective, suggesting that people potentially affected by terrorist incidents need to be supported to access effective and timely treatment. Outreach appears to be an appropriate approach for identifying affected adults; however, a more systematic method might be necessary to identify children and young people in need of support.

This evaluation has presented an opportunity for relevant agencies to learn from the experience of the Programme, in case of similar incidents happening again. The findings of this evaluation are consistent with the conclusions of the earlier evaluation of the 2005 London Bombings programme (Brewin et al., 2009), suggesting that future policy would benefit from consideration of the recurrent issues. It is important to bear in mind that the findings of this evaluation are positioned in a rapidly changing and complex field, and the response plans to future terrorist incidents are continually being developed.

Future work should include evaluations embedded in the responses to major incidents, with strategies aiming to reach the entire population of potentially affected individuals. Mapping out how people respond to trauma over time in wider contexts (e.g. group contexts) would help to identify further factors important for resilience and recovery. Also, it has been argued that PTSD after trauma may not be as common as depression or anxiety, and therefore a wider range of issues should be investigated as possible responses to trauma (NATO, 2009).



# 10. Recommendations

# From the information gathered in this study, we would recommend that the Department of Health and Social Care

- Ensure there is a system in place that would enable immediate response to terrorist attacks, building on the experience of previous responses and on NICE guidance.
- Define and agree roles and responsibilities of all government and non-government agencies involved.
- Develop guidelines for collection and management of contact details of all affected people, including options for how those details would be collected under various incident scenarios (e.g. in the UK or abroad, large numbers affected in one location or spread across the country).
- Appoint an organisation responsible for setting up a register of people affected as soon as possible after an incident.
- Arrange data-sharing agreements between the relevant agencies, within the constraints of the Data Protection Act, to facilitate direct communication with people affected.
- Prepare a plan for informing and communicating with people affected by terrorist incidents, including how internet and other means would be utilised; e.g. develop and publicise an accessible website with information about symptoms of trauma, PTSD, depression, anxiety and other potential problems, self-care, support available and how to access mental health services.
- Ensure that GPs and other health professionals are adequately trained to identify PTSD and other mental health problems to make appropriate referrals to evidence-based treatments.
- Utilise existing networks of IAPT services and services provided by non-NHS organisations to provide timely evidence-based advice, support and treatment.
- Develop guidance for approaching problems likely to be encountered when implementing a mental health response (e.g. assessing mental health needs, coordinating an appropriate response, ensuring equality of access to care).
- Consider a systematic approach for identifying children and young people in need of support.



#### 11. References

Bisson, J. I., Tavakoly, B., Witteveen, A. B., Ajdukovic, D., Jehel, L., Johansen, V. J., & Olff, M. (2010). TENTS guidelines: Development of post-disaster psychosocial care guidelines through a Delphi process. *British Journal of Psychiatry*, 196(1), 69-74. doi:10.1192/bjp.bp.109.066266.

Boscarino, J. A., Galea, S., Ahern, J., Resnick, H., & Vlahov, D. (2002). Utilization of mental health services following the September 11th terrorist attacks in Manhattan, NYC. *International Journal of Emergency Mental Health*, 4, 143–155.

Brewin, C.R., Scragg, P., Robertson, M., Thompson, M., D'Ardenne, P., Ehlers, A. (2008). Promoting mental health following the london bombings: A screen and treat approach. *Journal of Traumatic Stress*, 21(1): 3-8. doi:10.1002/jts.20310.

Brewin, C. R., Fuchkan, N., & Huntley, Z. (2009). Evaluation of the NHS Trauma response to the London bombings. Final report to the Department of Health Forensic Mental Health R & D Programme. University College London: Department of Clinical, Educational and Health Psychology.

Brewin, C.R., Fuchkan, N., Huntley, Z., Robertson, M., Thompson, M., Scragg, P., et al. (2010). Outreach and screening following the 2005 London bombings: Usage and outcomes. *Psychological Medicine*, 40(12): 2049-57. doi:10.1017/S0033291710000206.

Crole-Rees, C., Kitchiner, N., Roberts., N, Bisson, J. (2017). The Welsh trauma response: outpatient programme following the Tunisia terrorist attack in June 2015. Veterans NHS Wales & Cardiff & Vale Traumatic Stress Service.

Curtis, L. & Burns, A. (2016). Unit Costs of Health and Social Care 2016, Personal Social Services Research Unit, University of Kent, Canterbury.

Department of Health (2009). Emergency Preparedness Division. NHS Emergency Planning Guidance: Planning For The Psychosocial and Mental Health Care of People Affected by Major Incidents and Disasters: Interim National Strategic Guidance.

DiMaggio, C., Galea, S., & Madrid, P. A. (2007). Population psychiatric medication prescription rates following a terrorist attack. *Pre-Hospital and Disaster Medicine*, 22(06), 479-484.

Dyb, G., Jensen, T., Glad, K. A., Nygaard, E., & Thoresen, S. (2014). Early outreach to survivors of the shootings in Norway on the 22nd of July 2011. *European Journal of Psychotraumatology*, 5, 10.3402/ejpt.v5.23523. doi.org/10.3402/ejpt.v5.23523.

Fuchkan Buljan, N. (2016). Burden of posttraumatic stress disorder – health, social and economic consequences of exposure to the 2005 London bombings. PhD thesis. London School of Economics and Political Sciences.

Gruebner, O. (2014). Mapping the slums of Dhaka from 2006 to 2010. *Dataset Papers in Science*, 172-182. doi:10.1155/2014/172182.

King, N. (2012). Doing template analysis, in G. Symon and C. Cassell (eds.) Qualitative Organizational Research: Core Methods and Current Challenges. London: Sage.

Kroenke K., Spitzer R.L. (2002). The PHQ-9: A new depression and diagnostic severity measure. *Psychiatric Annals*, 32, 509-521.

McFarlane, A.C., & Williams, R. (2012). Mental health services required after disasters: Learning from the lasting effects of disasters. Depression Research and Treatment, 12. doi: 10.1155/2012/970194.

Mundt, J.C., Marks, I.M. et al. (2002). The Work and Social Adjustment Scale: A simple measure of impairment in functioning. *British Journal of Psychiatry*, 180: 461-4. doi:10.1192/bjp.180.5.461.

National Audit Office (2006). Review of the Experiences of United Kingdom Nationals affected by the East Indian Ocean Tsunami. November.

www.nao.org.uk/wp-content/uploads/2006/11/Review Tsunami Experiences.pdf



National Institute of Mental Health. (2002). Mental health and mass violence: Evidence-based early psychological intervention for victims/survivors of mass violence. NIMH Publication No. 02-5138. Washington, DC: U.S. Government Printing Office. Retrieved from <a href="https://www.hsdl.org/?view&did=441844">www.hsdl.org/?view&did=441844</a>

National Institute for Health and Clinical Excellence (2005). Post-traumatic stress disorder (PTSD). NICE clinical guideline 26.

Neria, Y., Nandi, A., & Galea, S. (2008). Post-traumatic stress disorder following disasters: a systematic review. *Psychological Medicine*, 38(04), 467-480.

NHS reference costs 2015-16. <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/577083/Reference\_Costs\_2015-16.pdf">www.gov.uk/government/uploads/system/uploads/attachment\_data/file/577083/Reference\_Costs\_2015-16.pdf</a>

North, C.S., Pfefferbaum, B., (2013). Mental health response to community disasters: a systematic review. *Journal of the American Medical Association*, 310(5):507-518. doi:10.1001/jama.2013.107799.

North Atlantic Treaty Organisation (NATO)/Euro-Atlantic Partnership Committee (EAPC). (2009). Annex 1 to APC(JMC)N(2008)0038 Psychosocial Care for People Affected by Disasters and Major Incidents: A Model for Designing, Delivering and Managing Psychosocial Services for People Involved in Major Incidents, Conflict, Disasters and Terrorism. Brussels.

Reifels, L., Pietrantoni, L., Prati, G., et al. (2013). Lessons learned about psychosocial responses to disaster and mass trauma: an international perspective. *European Journal of Psychotraumatology*, 4:22897. doi:10.3402/ejpt.v4i0.22897.

Spitzer, R.L., Kroenke, K., Williams, J.B., et al (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, May 22 166(10):1092-7. doi:10.1001/archinte.166.10.1092.

Te Brake, H., Duckers, M., De V.M., Van, D.D., Rooze, M., et al. (2009). Early psychosocial interventions after disasters, terrorism, and other shocking events: guideline development. *Nursing and Health Sciences*, 11, 336–343. doi:10.1111/j.1442-2018.2009.00491.x.

Te Brake, H., & Dückers, M. (2013). Early psychosocial interventions after disasters, terrorism and other shocking events: is there a gap between norms and practice in Europe? *European Journal of Psychotraumatology*, 4, 10. <a href="http://doi.org/10.3402/ejpt.v4i0.19093">http://doi.org/10.3402/ejpt.v4i0.19093</a>

The Rivers Centre in NHS Lothian (2016). Mental health support for people affected by emergencies: A Screen & Access programme for Scots affected by the terrorist attacks in Sousse and Paris in 2015.

TENTS Project Partners. The TENTS guidelines for psychosocial care following disasters and major incidents (2009). <a href="https://www.estss.org/tents/documents">www.estss.org/tents/documents</a>

Traumatic Stress Clinic (2008). London bombings mental health response: Sharing lessons learned. Camden and Islington NHS Foundation Trust.

Weiss, D.S., Marmar, C.R. (1997). The impact of event scale – revised. In: Wilson JP, Keane TM, editors. Assessing psychological trauma and PTSD. New York: Guilford Press. pp. 399–411.

Whalley, M.G. & Brewin, C.R. (2007). Mental health following terrorist attacks. *British Journal of Psychiatry*, 190, 94-96. doi:10.1192/bjp.bp.106.026427.

Williams, R., Bisson, J., Ajdukovic, D., Kemp, V., Alexander, D., Hacker Hughes, J., Rooze, M., Bevan, P. Guidance for responding to the psychosocial and mental health needs of people affected by disasters or major incidents. <a href="https://www.healthplanning.co.uk/media/1992/Principles for Disaster and Major Incident Psychosocial Care Final.pdf">www.healthplanning.co.uk/media/1992/Principles for Disaster and Major Incident Psychosocial Care Final.pdf</a>



# 12. Appendices 12.1 Appendix 1: Service use questionnaire

# Questionnaire for the Evaluation of the Screen and Treat programme for people affected by the terrorist attacks in Tunisia, Paris and Brussels

Please detach and complete this questionnaire if you have been directly affected by the events in Tunisia, Paris or Brussels. Please return the completed questionnaire in the stamped addressed envelope or email it to e.cyhlarova@lse.ac.uk. If you need help with completing the questionnaire, please contact Dr Eva Cyhlarova by email (e.cyhlarova@lse.ac.uk) or phone (020 7107 5222).

Your first name and surname:						
Your date of birth (dd/mm/yyyy):						
You are (please circle the one tha	t applies	to you): N	/lale / Fe	emale		
Please indicate which incident yo applies to you):	u have be	en affect	ed by <i>(p</i>	lease cii	rcle the one	that
Tunisia (March & June 2015)	Paris (N	ovember	2015)	Bruss	sels (March	<b>2016</b> )

Are there any children or young people under the age of 18 in your household who have also been affected by the incident?  ${\sf YES}$  /  ${\sf NO}$ 

This section asks ask for details of services you have used since the event.

1. Please indicate whether you have used any of the following services since the terrorist event as a direct result of your experience of the event:

Service	Use	ed?	Number of contacts since the terrorist event
General Practitioner (GP)	YES	NO	
Accident & Emergency	YES	NO	
Nurse	YES	NO	
NHS psychiatrist	YES	NO	
NHS psychologist or counsellor	YES	NO	
Private therapist or counsellor Please specify:	YES	NO	
Any other help Please specify:	YES	NO	



2. Since the event, have you been admitted to hospital as an inpatient **as a direct** result of your experience of the terrorist event? YES / NO

If yes, please complete the table:

	Hospital name and department/type of ward (e.g. Kings, neurology)	Reason for admission as an inpatient	Total days
1st referral			
2nd referral			
3rd referral			

3. Since the event, have you been referred for any treatment as an outpatient **as a direct result of your experience of the terrorist event? YES / NO** 

If yes, please state:

	Name of hospital/treatment centre and department (e.g. Kings, neurology)	Reason for outpatient referral	No. of contacts
1st referral			
2nd referral			
3rd referral			

The following section asks about the impact of the terrorist event on your work, education, family responsibilities, leisure or other activities.

4. Has your work/study been	affected in any of the following	ways as a direct result
of your experience of the	e terrorist event?	

a.	. Have you had to reduce your working or studying hours		
	as a result of the event?	YES	NO
b.	. Have you taken sick leave as a result of the event?	YES	NO
c.	. Have you become unemployed or ended/interrupted your		
	study as a result of the event?	YES	NO
d.	. Did treatment for PTSD or other mental health issues		
	related to the event help you to stay in work/study, or to return		
	to work/study earlier than you otherwise might have done?	YES	NO

5. Have your other daily activities, such as housework, family responsibilities or simil	ar,
been affected as a direct result of your experience of the event? YES / NO	

If yes, please describe how:

6.	Are there any other ways in which the terrorist event in Tunisia, Paris or Brussels
	has affected your ability to engage in work, studies, family responsibilities, leisure o
	other activities?

If yes, please describe:



# **12.2** Appendix 2: Unit costs

Unit costs for each service category were taken from PSSRU Unit Costs of Health and Social Care 2016, NHS reference costs 2015-16, or Fuchkan (2015), adjusted for inflation where necessary.

Service	Unit cost (£)
General Practitioner (GP)	36
Accident & Emergency	138
Nurse	43
NHS psychiatrist	138
NHS psychologist or counsellor	47
Private therapist or counsellor	79
Victim support	44
Support group	14
Hospital inpatient non-elective short stay	616
Hospital inpatient non-elective inpatient long stay (2 or more days)	2900
Hospital outpatient	135



The Policy Innovation Research Unit (PIRU) brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health.

We strengthen early policy development by exploiting the best routine data and by subjecting initiatives to speedy, thorough evaluation. We also help to optimise policy implementation across the Department of Health's responsibilities.

#### **Our partners**

PIRU is a collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), and Imperial College London Business School plus RAND Europe, the Nuffield Trust and the Public Health Research Consortium.

The Unit is funded by the Policy Research Programme of the Department of Health.













#### **Policy Innovation Research Unit**

Department of Health Services Research & Policy London School of Hygiene & Tropical Medicine 15–17 Tavistock Place, London WC1H 9SH