

Healthwatch Essex Trauma Card Pilot Evaluation

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Sharon Westfield de Cortez, Denise Hills, Kari Moore, John Wills, Indiana Montaque, and Danny Taggart





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Overview

The Healthwatch Essex Trauma Card has been created by the Healthwatch Essex (HWE) Trauma Ambassador Group (TAG), a group of people with lived experience of trauma. The group know first-hand how challenging it can be to access ordinary healthcare treatment. A trip to the doctor, dentist or hospital can create such a level of anxiety that people avoid seeking treatment, contributing to the development of chronic health conditions, and poorer long term physical and mental health. Complex trauma that is caused by interpersonal harms; child sexual abuse, physical violence, neglect, and sexual abuse in adulthood can lead to difficulties in interpersonal relationships, problems with trusting people in authority, and an aversion to physical and emotional intimacy. While these challenges can create problems, they are also an adaptive survival strategy in the context of having experienced interpersonal violence and harm. The Healthwatch Essex Trauma Ambassador Group members wanted to take their experiences of adversity in accessing healthcare and to turn them into a positive initiative that could enable them and other survivors to have more positive experiences. The Healthwatch Essex Trauma Card is the result of that work.

The card is designed to be a tool to empower cardholders to make the healthcare professionals they are interacting with aware of when they are experiencing the effects of trauma. Guidance for survivors can be found here: https://traumahub.uk/card-holders/. The Trauma Card is designed to raise awareness and educate professionals about trauma and how to more effectively support, and work with, those living with the effects of trauma. Advice for professionals can be found here: https://traumahub.uk/professionals/.

All Trauma Card holders carry the card to present in health and care settings when they experience a situation which has generated a trigger from them. Healthwatch Essex in collaboration with the University of Essex have conducted a pilot study of the Trauma Card's effectiveness, drawing on feedback from both Trauma Card users and the professionals they have shared the card with. Initial findings are encouraging, with preliminary feedback suggesting that the card can both empower trauma survivors in their interactions with healthcare professionals, while also educating practitioners on how best to respond to traumatised people accessing their services. While this is encouraging, more work

needs to be done on the Trauma Card development, feasibility and a larger scale evaluation before further claims on efficacy can be made.

Background context

Healthwatch Essex Trauma Ambassador Group created Trauma Cards to empower individuals who have experienced trauma to communicate more effectively with healthcare professionals. The cards are designed to be handed to a healthcare professional when a cardholder finds themselves in a triggering situation, to enable them to get the support they need.

The card has a QR code which, when scanned, provides more information to the healthcare professional about what the individual is experiencing and how best to help them. The cards were launched out on 1 November 2022 and used in GPs surgeries, hospitals, dentists, and a wide variety of environments where people access health or care support.

The Trauma Ambassador Group exists to help improve health and care environments for people who are living with the effects of trauma. The group's members have all experienced trauma, with a wide variety of different causes – ranging from domestic abuse, sexual abuse, exposure to crime, and bereavement. Trauma is considered very much an individual reaction and there is no exhaustive list of causes.

The initial idea for the Trauma Card was sparked by group member, 57-year-old John Wills from Brightlingsea, who is a survivor of child sexual abuse. John also brought knowledge from his later work as a therapist and discussion with other group members revealed that it was common to experience trauma being triggered in unexpected situations, such as at a dentist or during a health check. John felt that services had not improved much since he first reached out for support, so he wanted to create the cards to make things better for others. He said:

I carry the Trauma Card because I really need health professionals to understand that some of these situations are really quite difficult for me and make me very anxious. Sometimes there isn't the opportunity to open the conversation up about this subject, so simply by handing over the card

it starts the dialogue. I hope it will allow health professionals feel able to ask me what I need as a survivor of trauma. They forget just how traumatic and triggering some of these procedures can be for someone who has suffered trauma.

53-year-old Denise Hills, from Tilbury, was also involved in the project. Due to her experiences of domestic abuse, Denise experiences anxiety in medical and social care situations:

I find it very helpful – because of the anxiety I just shut down and can't talk. Knowing I've got the card means I'm less likely to be triggered. It's like that comfort blanket. It takes that stress off you.

To show the card in action, John and Denise helped create a short film with Michelle Wilkinson, an Advanced Nurse Practitioner at Beacon House, Colchester. Michelle says she is really excited about the ways the card could improve services if professionals engage with the cards:

I know these cards will be very helpful to many of the people I see day to day. Often because of their background – domestic violence, abuse, war or veterans' services – there may be sounds or noises that affect them in a way that we wouldn't appreciate. The card just gives us a heads up – an introduction that this patient might shut down within a certain situation. We can then use this to look at the website to give us tips and clues as to how to make the journey better for the patient. Things like offering a quiet area, double appointments, reducing distractions and sounds, may make this a more positive experience for our patients.

Sharon Westfield de Cortez, Information and Guidance Manager at Healthwatch Essex, founded the Trauma Ambassador Group to encourage people with lived experience of trauma to come together and shape health and care services in Essex. She said:

It has been a privilege to work closely with the Healthwatch Essex Trauma Ambassadors to produce the Trauma Card, which is a resource that I hope will help the people of Essex who are living with the effects of trauma get better outcomes from their interactions with health, care and wellbeing services.

When trauma survivors have a bad experience in a health care setting, it can result in them withdrawing and disengaging from health and care services completely, which means they don't have access to the health and care that they may need and are entitled to. The card can help to facilitate conversations and enable a level of understanding which otherwise may well not happen. It is a positive step towards creating equity for those of us living with trauma.

Research context

There is research evidence showing that many trauma survivors face significant barriers in accessing public services, such as oral healthcare services (Alyce, Taggart, Montaque & Turton, 2023). These barriers to healthcare treatment were identified by sexual violence survivors as a key research area as part of a project with the James Lind Alliance research Priority Setting Partnership (Varese et al., 2023). The Priority Setting Partnership identified survivors needing better understanding from healthcare providers about trauma, and how services can become more 'trauma informed to best support survivors and prevent retraumatisation.' (Varese et al.).

Despite these challenges faced by trauma survivors, there is increasing evidence that, with proper levels of staff training, trauma can be discussed in non-specialist settings without significant harm being caused. The Independent Inquiry into Child Sexual Abuse heard from over 6,000 adult survivors of child sexual abuse as part of their Truth Project. Adults from England and Wales shared their experiences of sexual abuse, talked about the impacts it had upon them and made recommendations for change. An evaluation of the project found that most of the sample found the experience of sharing their account to be empowering, it granted them a form of testimonial justice, and rates of retraumatisation were low (Barker et al., 2023 a). For those people who did experience retraumatisation, they reported that longer term follow-up support would have been helpful. Furthermore, a linked study investigated non-specialist staff's experiences of working with survivors of child sexual abuse and being exposed to trauma related materials. While working with trauma did impact staff, the study found that if they were well supported and provided with reflective spaces, that the negative impacts were limited (Barker et al., 2023 b). These studies suggest that long held

taboos about talking about child sexual abuse, that it will 'open a can of worms' for the survivor and negatively impact the listener may be overstated, and that interpersonal trauma can be safely talked about if all participants in dialogue are well supported.

The examples described above suggest a wider societal shift in society's ability to talk about difficult social topics such as sexual abuse and other forms of interpersonal violence that lead to traumatic injuries. Trauma is becoming an increasingly accepted marker of legitimate victimhood, that can facilitate access to other form of justice, reparation and social inclusion (Wright, 2018). However, professionals continue to feel uncertain about how to have these conversations safely, and this can lead to low levels of disclosures (Winters et al., 2020). Despite this anxiety, research suggests that professionals asking directly about abuse histories have a positive impact on survivors' ability to disclose (Solberg et al., 2021). One of the factors that facilitates professionals talking more about trauma histories are knowledge, skills and attitudes, in particular the skill to be able to sit with a non-judgmental attitude and listen to the person's disclosure (Scoglio et al., 2020). Health and care professionals need support to develop these skills and attitudes and the knowledge about trauma to be able to manage disclosure effectively. There is also some evidence suggesting that interventions codesigned by trauma survivors to enable engagement in services can be more environmentally attuned and responsive to specific trauma symptoms than topdown professional led interventions (Wright et al., 2023). In looking to increase professionals' confidence in working with people with trauma, it is important survivors themselves are involved in the process of designing interventions, as it can increase authenticity, ecological validity, sensitivity to trauma needs, and increase moral credibility with other survivors.

Methods

The Trauma Card pilot was launched on 1 November 2022. Concept development involved consideration of all TAG members' ideas, such as the language and wording, the type of material and print, whether the product took the form of a card, broach pin, or as a sunflower lanyard. Working through the different ideas that people bring can be challenging. But by working together, the group recognised that getting 100% agreement on everything through a 'one-size fits all'

approach was not going to be possible, but a 90% consensus would be achievable. Further ideas were to add a QR code to link people to more information and services, hosted on a webpage that was co-designed by ambassadors (with everyone voting on the stock images used). Giving deadlines for comments was helpful, as well as being flexible with the structure and layout. The ethos was 'guiding rather than telling'.

As discussed, the TAG were pivotal in deciding every aspect of the card through discussions in meetings, email conversations, and their group WhatsApp. This included the content on the two faces of the card and the webpages, the text for the accompanying flyer, and all images. Different examples of fonts, paper quality and web page images, for example, were sent to the group to decide on what was most appropriate. Individual TAG members also consulted with trauma survivors in their own networks to gain wider collaboration and consensus on the best approach.

Once the Trauma Ambassador Group agreed on the design of the card and agreed that a QR link was a helpful addition, work was done on a website to provide further information to both survivors (card holders) and professionals (card receivers). The card holders link provided some background information for survivors on how the card had come about, the fact that it was designed by other trauma survivors, as well as providing information on how to get access to cards. It also included a general introduction to trauma written in accessible language, and links to further information from specialist websites such as Mind and the UK Trauma Council. The link for professionals provided information about the Trauma Card and how it signified they were dealing with a person who had experienced trauma. It said;

If you have been presented with a Trauma Card, the person you are interacting with is living with the effects of trauma, and the situation you are currently in has generated a trigger for them. You may not have been aware that they were affected by trauma, and you may not be able to pinpoint what has occurred to cause the reaction. However, neither of these things are your primary concern. What matters is how the situation now progresses, as what happens will likely have a significant impact on the relationship/engagement going forward.

It went on to make suggestions about how to interact with the person; to empathise, be patient and to reassure. It also contained the same introduction to trauma as on the card holders website and links to external websites.

Once the concept had been finalised and the background materials agreed the Trauma Card was launched by HWE by a range of social media platforms. By 11 November 2022, 2,000 cards had been requested. As of March 2024, over 15,000 Trauma Cards have been distributed. They have been sent to people and organisations all over the UK, and HWE have also liaised agencies in Eastern Europe and the USA who are interested in the model.

The Trauma Card link website for both card holders and professionals contained an option to provide feedback on their experience of using the card as either a trauma survivor or card receiver. The feedback took the form of asking about service context for card use, confidence of survivors, reason for using the card, how it was received by the service and what impact it had on service provision. A similar set of questions was also asked of service providers about their experience of receiving the card, what they did differently after receiving it and what they learnt from the interaction. A full list of survey questions can be found in Appendix A.

Findings

As part of the pilot project, 91 card holders completed feedback on their use of the card and their experiences using the card as a tool to communicate their history and needs in various contexts. The results from the project showed that the Trauma Card was used in various health and social care settings; including at doctor's appointments, the opticians, interactions with social services and in work hearings. The broad variety of settings in which the Trauma Card was used shows that survivors felt the card was appropriate to use in various personal interactions with a variety of professionals. The Trauma Card was used the most when interacting with doctors (30 card holder used the card in this context)

Feedback was captured around the card holder's confidence using the card and how effective they felt the card was. A significant proportion of card holders felt confident using the card (40%), however, 37% did not feel confident using the card. This offers useful insight into potential future developments for the use of the

Trauma Card, and supporting more survivors to feel confident using the card when they feel it is needed. Some of the quotes from survivors using the card indicated that they felt they had 'something on their side' and they 'felt empowered'.

In terms of effectiveness, an overwhelming majority (99%) felt that the card was effective. When using the service, the feedback indicated that the card had a positive impact on trust and engagement. A large majority of users (95%) felt the card had a very positive impact on their trust in the service, and 92% felt the card had a very positive impact on their trust in the provider. In addition, 97% of respondents outlined that the card had a very positive impact on their engagement in the service. It could be concluded that the Trauma Card allowed card holder to have confidence in the service and the service provider and allowed them to have a more active role in the use of the service.

This connects to feedback about card holders' feeling of safety in the service. The card had a very positive impact on feeling safe in the service for 94% of card holders, and 99% felt the card had a very positive impact on them feeling in control during the contact. The card had a very positive impact on overall experience of the service for 95% of people and 94% felt that the card had a very positive impact on them feeling safe during the contact with the service. The vast majority (99%) felt the card had a very positive impact on them feeling in control during the contact. When considering communication needs during the contact, 98% of respondents felt that the card had a very positive impact on this. In addition, 98% felt that using the card had a very positive impact on the professional's practice. One respondent mentioned as part of their feedback that 'They read it and asked me how they could help. They have never done that before' and another respondent mentioned that 'They connected with me more'.

Overall, 100% of card holders would use the card again and all the respondents fed back that they would use the service again based on their experience of using.

14 professionals completed feedback based on their experience of receiving the card. The professionals operated in various health and social care settings, including trauma support, healthcare, NHS, domestic abuse services, and support groups. All the professionals who completed the feedback stated that this was their first encounter with a tool such as the Trauma Card. All professionals felt that the Trauma Card was effective in communicating information about how the service user might experience the service.

All professionals felt the Trauma Card improved the appointment/contact. Some of the feedback included more information about how professionals found the card: 'It's a huge reassurance, discreet yet empowering'; 'It just opened up the conversation which was great'. All respondents to a question exploring improvement of practice felt that the Trauma Card improved their practice and made them think differently about how survivors of trauma might experience their service. All professionals felt the Trauma Card improved the service users' engagement in the service. Everyone who received the card felt it was very easy to find information using the QR code on the Trauma Card.

Overall, all the professionals who received the Trauma Card and completed the feedback felt that the card was very useful.

Summary of Findings

Based on this initial pilot study, there is preliminary evidence to suggest the use of a Trauma Card in accessing healthcare services can be empowering and all respondents felt the card was effective in facilitating engagement with professionals. All respondents said they would use the Trauma Card again in the future. Similarly, initial feedback from a small number of professionals was encouraging. They felt it improved the quality of the interaction and the digital interface was accessible and useful.

Recommendations

Findings from a linked study co-designed by the Trauma Ambassador Group looked at the experiences of sexual violence survivors from Essex engaging with oral healthcare services (Montaque, 2024). In this study the views of oral healthcare practitioners was sought to gain their views on barrier and facilitators to accessing treatment for this population. One of the findings was that the consultation session was too late for a conversation about additional needs about trauma to begin, due to limited time and practitioner uncertainty. Practitioners suggested that advance disclosure might be useful in enabling adjustments to be made, saying this was aligned with other patient additional needs in these settings. One suggestion is that a digital card could be

designed to send in advance of appointments, with the option for a physical card to also be used if preferred by the cardholder.

- While initial feedback is encouraging, more detailed research needs to be undertaken to investigate the feasibility, utility and effectiveness of the Trauma Card. Research could focus on card holder views on what differences the card makes to them and how and where they use it. Also, recommendations for improvement could also be elicited. From the professionals' viewpoint, it would be important to explore what difference if any the presentation of the Trauma Card made to their practice and to gain some specific feedback about what their suggestions are for the website content they accessed via the QR code. It would also be worth finding out from them to what extent the Trauma Card intervention has changed their confidence and skill sin working with trauma survivors.
- The background information and recommendations provided on trauma on the Trauma Card website are of real value and written in an accessible style. These could be developed further to include best practice, evidence-based advice on how to work in a trauma informed way. This could be done collaboratively with trauma survivors to ensure lived experience expertise continues to be at the heart of the intervention.

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Appendix A

Trauma Card Evaluation Survey Questions

For cardholders:

- 1. In what setting/service did you use the card?
- 2. How confident did you feel using the card?
- 3. Please tell us why you felt the way that you indicated in Question 2.
- **4.** Was the card effective in communicating what considerations you may need when using the service?
- 5. How did the service provider respond once they received the card?
- 6. How did the card impact on the service providers practice?
- 7. How did the card impact on your trust in the service?
- 8. How did the card impact on your trust in the healthcare/service provider?
- 9. How did the card impact on your engagement with the service?
- 10. How did the card impact on your experience of the service?
- 11. How did the card impact on your feeling safe in the service/appointment?
- **12.** How did the card impact on your feeling in control of the appointment/meeting?
- **13.** How did the card impact on the communication between you and the service provider?
- **14.** How did the card impact on the practitioner/service-providers practice during the appointment?
- **15.** How would you improve the card?
- 16. Based on your experience, would you use the card again?
- 17. How would the card impact on your likelihood of using the service again?
- 18. Overall, how was your experience using the card?

For professionals:

- 1. What setting/service do you work in?
- 2. How did you experience receiving the card?
- **3.** Is this the first time you have encountered correspondence like the trauma card?
- **4.** Was the card effective in communicating information about how the service user may experience your service?
- 5. Did the trauma card improve the appointment/meeting?
- 6. Please say how the trauma card improved the appointment/meeting.
- 7. Did the trauma card *change* your standard practice?
- 8. Please explain how the trauma card changed your practice.
- 9. What impact did the card have on your practice?
- 10. Please explain the impact that the card had on your practice.
- 11. Do you think the card improved the *service user's engagement* in your service?
- 12. Please say how you think the card improved the service user's engagement in your service.
- **13.** Has the trauma card made you think differently about your service for survivors of trauma?
- **14.** Please say how the card made you think differently about your service for survivors of trauma.
- **15.** How easy was it to use the card to find information?
- **16.** How would you improve the card?
- 17. Overall, did you find the trauma card useful?