

# Trauma Service Redesign

CAPS, as part of the ongoing Public Social Partnership involved in the redesign of the Rivers Centre has been asking people what language should be used in information describing a Lothian Service for people who have experienced trauma.



This word cloud represents the most important words and topics that people said should be considered when designing a trauma service.



Public Social Partnership

Scottish Charitable Incorporated Organisation SC021772





## What is *CAPS*?

CAPS is an **independent advocacy organisation** for people who **use or have used mental health services**.

CAPS **works with people who use or have used mental health services** as individuals or as members of a group to **set their own agenda**, to find a **stronger voice**, to **get their point across**, and **influence decisions** which affect their lives.

CAPS provides individual and collective advocacy in **Midlothian and East Lothian**. CAPS also has several **Lothian-wide** experience-led projects.

**Individual Advocacy** is about working **alongside a person** to help them **express their views** and have more **influence** over **decisions** being made about their lives.

**Collective Advocacy** is about **groups** of individuals with a **common cause** who come together to **raise awareness**, **campaign** and **influence** service planning and provision.

CAPS is an **Independent Advocacy** organisation.  
This means that it:

- Puts the people who use advocacy first
- Is accountable
- Is as free as it can be from conflicts of interest
- Is accessible

**CAPS is a Scottish Charitable Incorporated Organisation  
SCIO Number SC021772**

**CAPS is funded by East Lothian and Midlothian Councils, NHS Lothian, and  
East Lothian Community Health Partnership.**

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## **The story so far....**

**There is a collaborative project (Public Social Partnership) going on at the moment to make trauma services in Lothian better. Currently these services are offered through the Rivers Centre based at the Royal Edinburgh Hospital site.**

### **What is the Rivers Centre?**

- A service offered by the NHS for people who have experienced trauma.
- Scotland's leading provider of adult traumatic stress services
- Specialises in the assessment and treatment of trauma-related problems.
- It provides services from individual therapeutic interventions to advice and consultancy for organisations.

### **How does the service operate just now?**

- It is hospital-based
- Organised by age range
- It operates an opt-in system
- There are long waiting lists

### **What might be different?**

So far the Public Social Partnership has looked at ways that they can make any new service;

- Person and family centred
- A secure base
- Include meaningful activities and evidence based practice
- Provide a space that encourages feedback based on personal outcomes – 'distance travelled.'

## **How are CAPS involved?**

**As an interested party on the Public Social Partnership, given CAPS independent mandate and what people have told us about the importance of language, we were asked to undertake a consultation with people on this topic.**

### **What we did....**

CAPS designed a project to allow a steering group of interested people to come together and decide how to design a consultation asking the questions about the language that should be used in publications by the new service and also what their thoughts on the design of a new service should include.

We received 36 responses interested in being part of the project, 20 of whom were interested in forming a steering group to shape the project on the consultation further.

### **Statement of purpose**

The purpose of the steering group was to design a consultation that looks at the language that people want to see used in any information that is produced by a trauma service. The consultation would also look more widely at what people would want from a trauma service.

CAPS role is to make sure that the conversations of people who might want to use this service are meaningfully included in decisions during the process of redesign.

### **What did we do?**

CAPS facilitated 4 sessions with members of the steering group to look at designing a questionnaire to be distributed across the Lothians.

A survey monkey questionnaire was produced from discussions within the group and we received 37 responses.

The results of the consultation are considered on the following pages.

## What did we ask?

The steering group decided on several core questions around people's previous knowledge and experience of the Rivers Centre:

- 55% of respondents were aware that the Rivers Centre existed and 32% had tried to access the service previously.

Of those who had not tried to access the service some of the reasons given for this was:

- Didn't know about the service
- Thought that a professional referral was required
- Didn't know if experiences would be considered traumatic
- Not interested in the service offered there
- No referral offered

We asked about people's experience of accessing the Rivers Centre or other trauma services:

People said that they found accessing any trauma services very difficult and that there were **long waiting times** if they had been referred. There was a feeling that there was a problem with 'trauma awareness' in gateway services. People said that **GP's knowledge** of what was considered trauma and the services available was limited. People also talked about the fact that the need to fit a **'tick box' criteria was very frustrating** when trying to access service. The lack of information about services in general and feedback for being denied a service was highlighted in responses.

People who had accessed the **Rivers Centre** said that **staff were very supportive** and the **environment was peaceful**. They also commented that the treatment and information given there was helpful and they found the staff very competent.

*"Not enough information of what is available"*

*"....I was turned down for treatment there.....told that I needed specific trauma treatment....I have never been able to access specific trauma treatment on the NHS."*

*"I have very good support within mental health services but it still took many years to realise that there was a dedicated trauma service."*

*"Very difficult and long process"*

*"...No GP has ever suggested any referral for me other than counselling....I generally find that GP's have or give me very limited information about what services are available, and don't take a lot of time to ask me questions to establish what I need."*

*"Despite a PTSD diagnosis and referral from my OT I was not given a place at Rivers centre which I don't understand."*

*"Still waiting for a response"*

*"It provides two amazing courses I know of, Survive and Thrive and compassionate focused therapy All information was barrier breaking and trainers beyond competent."*

## What is important about how the service behaves?

We asked people how they would like people who worked in the service to behave towards them and what they would like the atmosphere of the service to be:

When thinking about how they would like workers to behave towards them, the most common theme was **'non-judgemental'**. People talked about being treated as an equal, like a peer relationship and not to have a patronising or controlling attitude. **Honesty, respect, kindness, dignity and patience** were high on people's agenda for how they would like to be treated.

A large number of responses indicated the need for a **trusting relationship** to be developed and that they wanted to be engaged with as whole human beings and not to be viewed only through the lense of their diagnosis or behaviours.

A few people mentioned the importance of being able to have **ongoing contact** with the service after any treatment was complete to allow for any questions, and to invite feedback from the service.

*"Validate my experiences, work with me not on me.."*

*"Kind and compassionate, non-judgemental, understanding"*

*"Open and honest.."*

*"..Very patient, it can take a long time to build the trust needed to be able to open up about traumatic experience..."*

*"With respect and acknowledge that I am more than the sum of my behaviours"*

*"Treat me as human being and not just a statistic/diagnosis/behaviour."*

*"Be clear about their roles and boundries."*

*"...invite and facilitate feedback from service users to optimise improvement and service development"*

*"As a peer"*

## What is important about the atmosphere of the service?

In answer to what atmosphere people wanted from a service, responses that included terms like **calm, safe, welcoming, friendly, relaxed and non – clinical** were prevalent throughout.

People told us that green spaces and plants would be good to have.

Completely **separate spaces available** for different genders or age groups would be valuable.

*"...a place that feels safe, not overly clinical – safety from further abuse – the priority"*

*"...attitude that enables you (me) to feel safe, probably as important as physical environment."*

*"Not too clinical, more of a friendly atmosphere."*

*"Open, warm, friendly"*

*"...green space and plants would be good (real plants, not plastic ones!)"*

*"Calm, relaxed, respectful"*



## How should the service and the people who access it be described?

The next part of the questionnaire looked at what people felt was the best way to describe any new service and how they would like to be described as someone accessing the service.

There were three terms that people felt, relatively equally, were good to describe a service, these were;

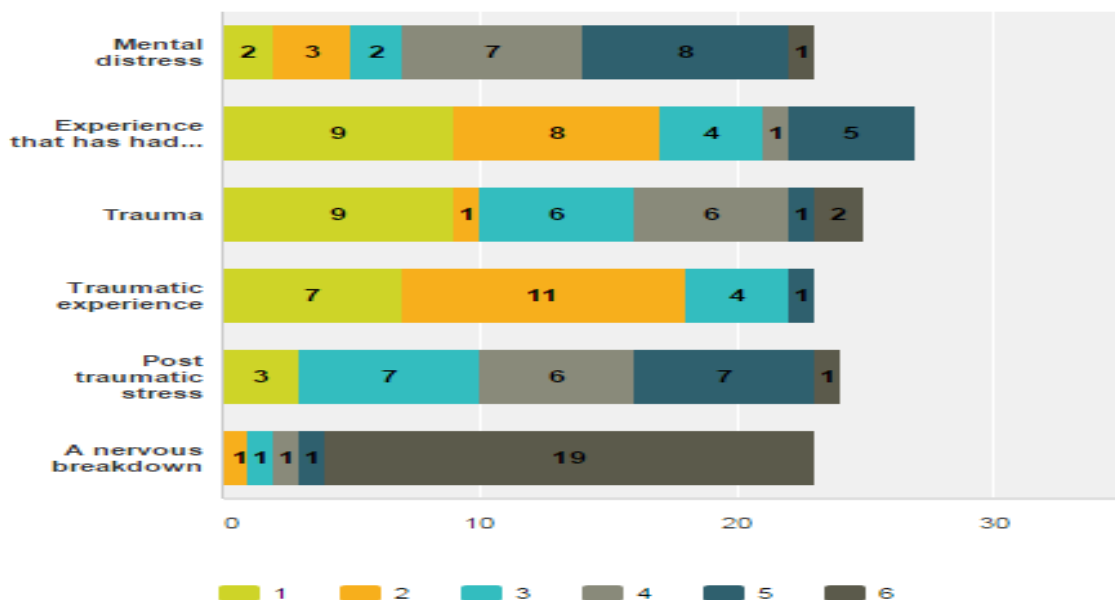
- **Trauma**
- **Traumatic experience**
- **Experience that has had a long-term or significant negative effect on you**

Other ways that people thought may be good to describe the service were:

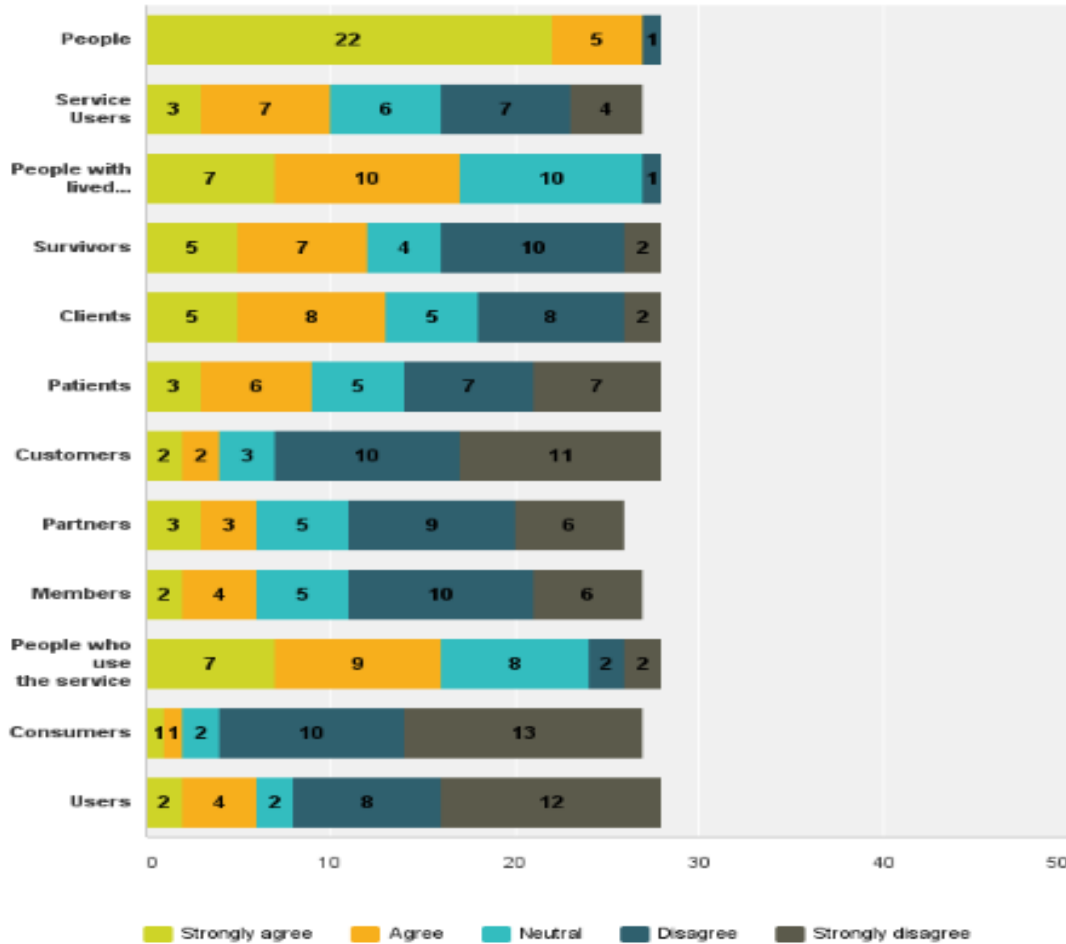
- Trauma Informed
- A listening service when you need it most
- Trauma Services Centre
- Extreme stress, distress and or trauma

Many people felt it was important to keep the word 'trauma' in the title somewhere as it seems to convey the right message for a service like this but people also felt that a bit more description in any information provided would be really helpful.

This chart shows the full list of responses. The options shown for descriptions were decided on by the steering group.



Similarly with how people would like to be described within a service the steering group arrived at a list of terms that have all been used to describe them when accessing services at some point and used these to ask the question within the survey. The chart below shows the responses:



From this we are able to see that a **majority** of people who answered the question **strongly agreed** that **‘people’ is the preferred term**, and that terms like **‘Users’, ‘customers’ and ‘consumers’ were very unpopular.**

## What is important about the information that is provided by a service?

The next section of the questionnaire dealt with what information was important to have before somebody accessed the service, how this should be presented and what was important about the location of the service.

**100%** of people who responded agreed that the following things should definitely be included in information provided about a service before they accessed it:

- Information on **what different therapies, activities and treatments** are on offer.
- **Who you can take with you** to an appointment
- Information about where the service is
- **Transport information** and parking

Of the other options that the steering group felt might be important to people before accessing a service:

57% of people thought that photos of people who work there would be helpful

71% of people would like photos of the outside of the building

96% felt it would be good to know how to access different options in the service

67% would like to have information on how to have your say about how the service works

Other things that people felt were important to include in any information people received before accessing a service were:

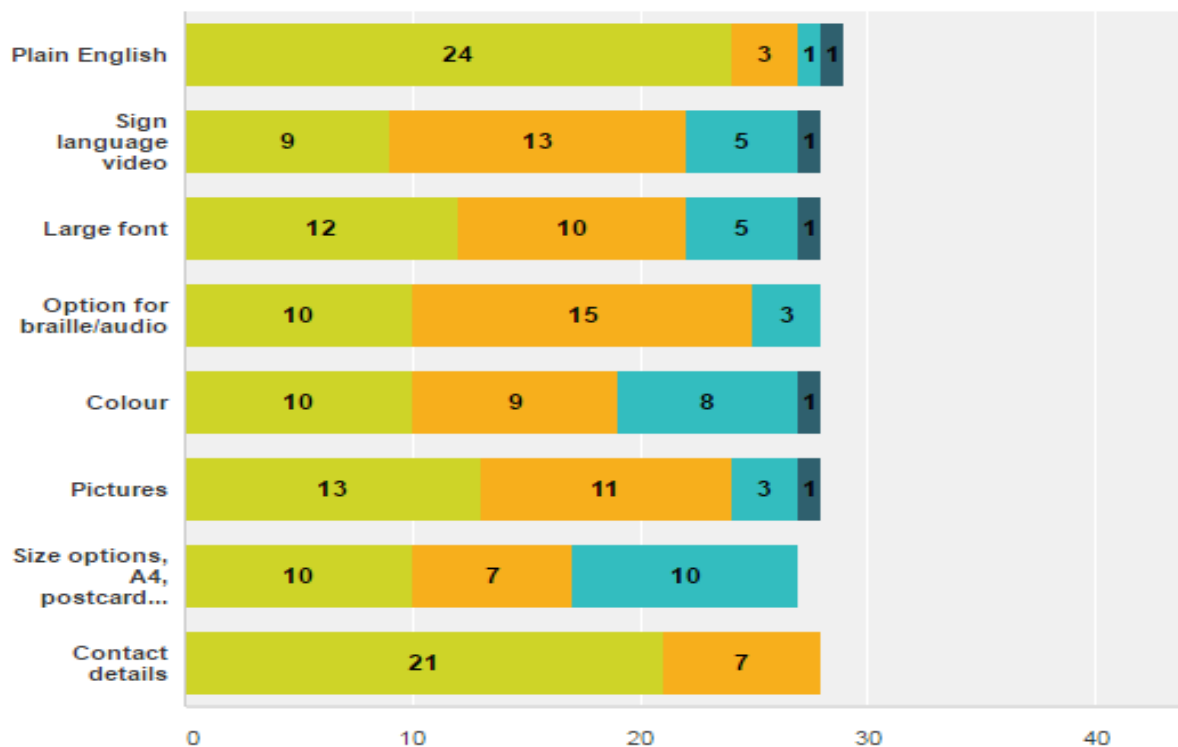
- Information on **waiting lists** for different parts of the service.
- What support would be given about options if a service at the centre was not offered?
- **Complaints and feedback** mechanism
- How to leave a message/what to do if you cannot make an appointment
- **Confidentiality** and privacy policy
- Information sharing policy
- **Stories from people who have previously used the service**
- Information about the ethos of the service

*“What might be useful would be some stories from people who have used the service previously so you can get a feel for what things might be useful/how it might help in reality”*

*“Contact numbers where to leave a message – most NHS services don’t offer answer phones or email contacts”*

*“An idea of what/how things might be reported back at end e.g. letter to GP”*

When looking at what would be useful to have in design and format of documents, posters or leaflets, the chart below shows what people felt were the most important elements:



Keeping the **language plain and accessible** was the most important thing people felt was necessary when producing information, but also that contact details were clearly shown.

We asked people where they thought would be a good place to find out about a service like this, and where information on the service should be available.

**The most popular options for where information needs to be accessible were:**

- **96%** of people strongly agreed or agreed that information should be available in **GP surgeries** with **4%** disagreeing
- **92%** of people strongly agreed or agreed that a **dedicated website** advertising the service would be very useful, 4% answered neutral and **4%** disagreed.
- **89%** of people strongly agreed or agreed that **groups** that they already attend should have information on a service like this. 11% were neutral.
- **85%** of people strongly agreed or agreed that **libraries** should hold information, 11% of people were neutral and **4%** of people disagreed

**Two of the options were more evenly split in agreement and disagreement:**

- **55%** of people strongly agreed or agreed that **cafes** would be useful places to have information available. 38% of people were neutral and **7%** of people disagreed with this choice.
- **42%** of people strongly agreed or agreed that **public advertising** (bus stops etc) could be good places to make information available, 35% were neutral and **23%** disagreed.

**Three of the options available had a proportion of people who had strong feeling that these would not be positive or appropriate place for information on a service like this:**

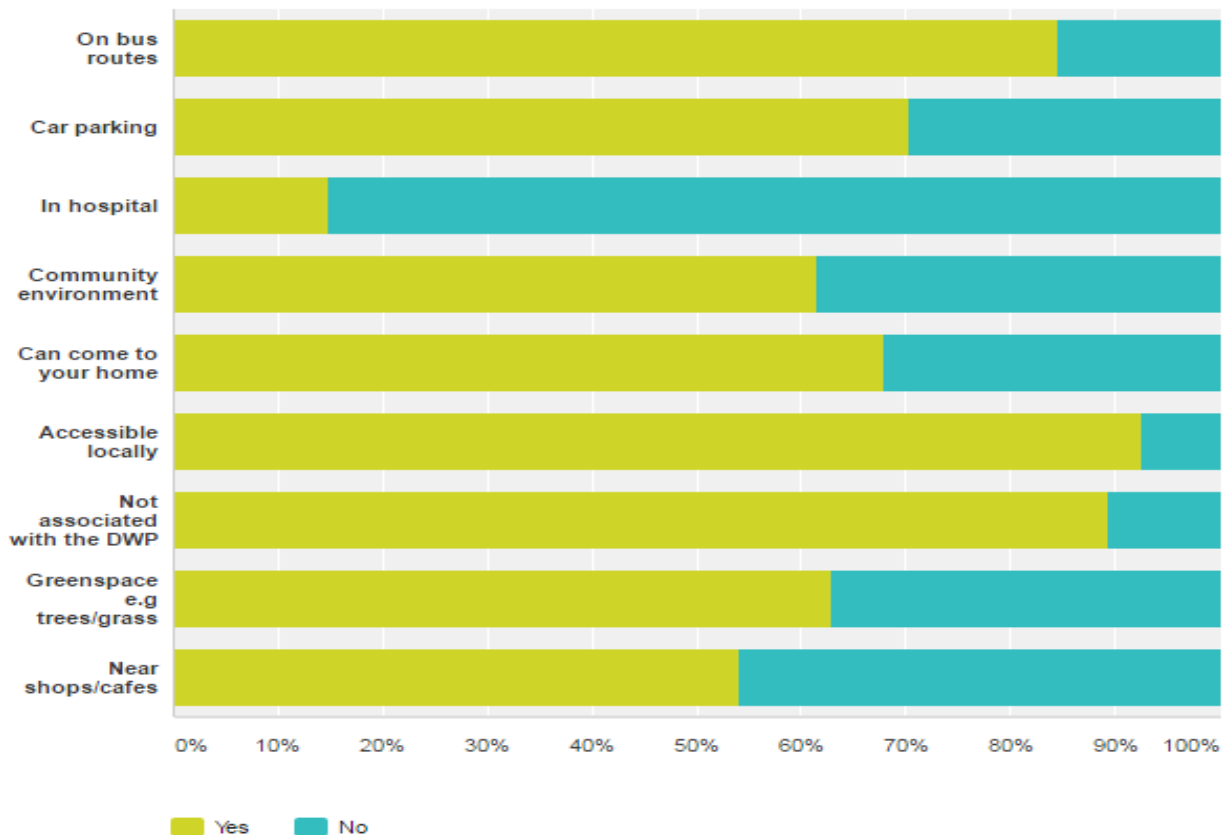
- **71%** of people strongly agreed or agreed that **social media** was a positive way of distributing information, 11% were neutral, 14% of people disagreed with this and **4% strongly disagreed**
- **68%** of people strongly agreed or agreed that information should be provided in **schools**, 24% were neutral and **8% split evenly between disagreeing and strongly disagreeing**
- **72%** of people strongly agreed or agreed that information provided through **employers** would be useful, 15% were neutral, 7% disagreed with this option and **3% strongly disagreed.**

## What is important about where a service is located?

From the responses about what issues should be considered when choosing a location, the results clearly show the people feel most strongly that **access to the service either within their local area or on good public transport routes was very important.**

A significant number of people felt that it would good for the service to be able to come to their own home.

There was very strong feeling that the **service should not be located in a hospital environment** and should **not have any association with the DWP or where benefit assessments are held.**



## Access all ages?

A separate question was asked within the consultation to look at how a trauma service could plan for people of all ages using the same building.

- Having **separate waiting areas for adults and children** was identified as an important feature of any service. Making sure that these spaces did not have to cross over and that the design and decoration was appropriate for each.
- Ensuring that **information about the service was accessible in different formats for different age groups**. For instance, making language age appropriate for younger people accessing the service, but also making adjustments for older people as well.
- Keeping the **attitude of non-judgment as paramount** in decisions about design was very important to people, for example older people not feeling that they were in the 'geriatric' category.
- A keen awareness by staff of adult and child protection issues is highlighted as extremely important. Ensuring that **ALL people feel safe in the environment** and the possibility of negative interaction is kept as small as possible.

*"Information that is accessible for people of all ages."*

*"Would be great if age barriers could be broken down but would still need separate areas...people over age 65 must NOT be made to feel they are in geriatric category."*

*"...appropriate design of reception areas, decoration, noise levels and privacy need to be carefully considered.."*

*"Protection of children and vulnerable adults. Children and young people will need a different type of atmosphere and environment, scope for different activities."*

## All of you – what do you need?

We asked what other things a service like this could do to be inclusive of people's experiences, identities and life circumstances.

Some of the things that people identified were;

- **Flexibility** in times of access to the service.
- **Non-gender specific** toilets
- **Non-religious** based service
- Ability to **request a specific gender** of worker
- Staff well trained to **communicate** with people with Autistic Spectrum Disorders

*"To be able to request a female worker."*

*"If there are waiting/public areas or spaces it would be good idea to let people know that they should be prepared for a mix of genders using this space."*

*"To be visibly/actively LGBT affirmative."*

*"In employment – needs to be flexible."*

*"An attitude of belief - at a minimum accepting that it's real to you."*



## Anything else...

The final question asked if there were any other things people thought were important about what a trauma service should look like:

*"Staff should include peer workers."*

*"Gender sensitive and gender specific services especially important for woman surviving child sexual abuse."*

*"Joined up with other services that work in trauma related fields so that people can move between them easily."*

*"It would be very useful if my access to the service wasn't time limited."*

*"..find out how other people feel about mixed genders or the gender of people working there. Some women may find the presence of men difficult."*

*"Main message feels as if it has to be – ensure I feel heard, and safe from further abuse."*

*"...needs to support people in a variety of creative ways and give people space to access different types of activities – i.e. arts/crafts/music/physical activity/gardening/outdoor etc."*

*"electronic communication is the most accessible to me. It would be great to have some meaningful electronic channel, unlike the NHS. We could make use of VOIP tools (like Skype but secure) that are available with modern web browsers."*

## Who responded...

- The ages of those who responded to the survey ranged from 18 – 65 with the highest proportion of people - 32% - in the 55-65 year old bracket, and the lowest - 11% - in the 18 – 26 bracket.
- People living in Edinburgh made up the largest proportion of those who completed the survey at 68%. 14% of people from Midlothian, 11% of people were from East Lothian and 7% from West Lothian.
- 36% of people had caring responsibilities
- 68% of people completing the survey identified as having a mental health issue. 14% said they did not have a mental health issue and 17% of people marked other with comments:

***“complex PTSD – diagnosis from an NHS psychiatrist.”***

***“I have a diagnosis; that diagnosis means that I can protect myself using disability discrimination legislation and the equalities***

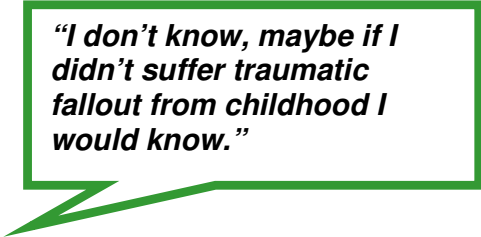
***“PTSD”***

***“I am neurodiverse..(f\*\*\* the DSM etc)”***

***“Previous diagnosis of post natal depression, anxiety, trauma...”***

- From the responses received 29% of people consider themselves disabled, 57% do not and 14% prefer not to say.
- 56% of people consider themselves Scottish and 44% of people consider themselves British.

- When asked about ethnic identity, not relating to nationality or place of birth but about the group they felt they belonged to, 42% of people identified as either Scottish or White Scottish. 21% of people said British or White British. 16% of people said White, 4% identified as English and 4% Caucasian. 13% of people said they did not have any ethnic identity.
- The gender split of respondents was 82% women and 18% men.
- 11% of respondents identified as transgender.
- When asked about sexual orientation/sexuality 63% of people answered Hetrosexual/Straight. Of those within the LGBT community 26% identified – 11% Bisexual, 8% Lesbian/Gay woman, 3% Gay and 4% queer. 8% of people preferred not to say and 3% of people chose other with comments:



***“I don’t know, maybe if I didn’t suffer traumatic fallout from childhood I would know.”***

- When asked the question about what religion or belief people identified with 42% of people said they did not identify with any religion, 16% said agnostic, 10% answered Church of Scotland, 6% Catholic and 6% Christian. 20% identified with their own beliefs.

## What were the main themes of the consultation?



### Atmosphere:

- People want the atmosphere of any service to be **welcoming, friendly, relaxed**.
- **A non-clinical environment** was high on people's agenda for how the building should both appear and feel, however a recognition of the fact that there should be **appropriate areas for different age groups** was identified.



### Interactions:

- Overwhelmingly people talked about **not wanting to feel judged**. Being seen as a whole person and not defined by diagnosis or behaviour was extremely important to people.
- **Patience** was highlighted as particularly relevant in order to build up a **trusting relationship** which was considered paramount for a service dealing with trauma.



### Information:

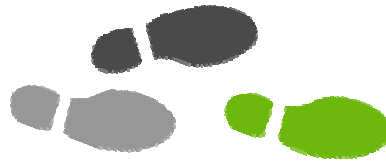
- **Confidentiality** and information sharing was highlighted throughout people's responses in several different contexts, from feeling that there is good transparency of where information goes as well as a feeling of confidence that personal information is kept safe
- Knowing what to expect from the service is important, how to **access different therapies**, what waiting times are likely to be, and how to navigate through different treatment options etc. People told us that it was important to have this information before they accessed the service.



### Service issues:

- The service needs to be **gender sensitive** and a **feeling of safety** is of paramount importance to people.
- A lack of knowledge and understanding of trauma and related issues with GP's and other primary services is problematic for people

## What happens next?



This report will be presented to the interested parties at the next Public Social Partnership meeting. CAPS Advocacy workers will continue to attend the Public Social Partnership meetings for the redesign of the Rivers Centre to make sure peoples comments are heard and included.

The information from this report and the consultation will influence decisions about the publicity that is used within the final project

CAPS will ensure that this report is distributed to everybody who expressed an interest in being part of this project.

CAPS will publicise this report on our website through our networks and will continue to present it at other relevant forums.





## **Acknowledgements**

CAPS would like to thank everyone who was involved in the planning, collaboration and organisation of the steering group.

For all those who participated in the consultation CAPS would like to thank you for your time. It was great to see so many people interested and involved in this topic and some really interesting ideas came out of the consultation to take forward for the future!

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