

## Co-produced patient pathway for sexual health follow-up for children and young people using a Paediatric SARC – facilitating elements of self-care and testing.

### Background

Childhood sexual abuse (CSA) is increasingly recognised and the impact often lifelong <sup>1</sup>. At least 15% of girls/young women and 5% of boys/young men experience some form of sexual abuse before the age of 16 <sup>2</sup> after which they may be offered sexual health follow-up (SHFU) from a Paediatric Sexual Abuse Referral Centre (SARC). For children and young people (CYP) and their carers, the visit may be anxiety-provoking or risk revisiting trauma. For referring teams, there may be barriers to finding an appropriate provider, especially for CYP under 13 who cannot attend standard Sexual Health clinics. For primary care providers, these consultations may feel beyond day-to-day competencies.

### Why was the project needed?

The Bridge paediatric SARC, based in Bristol, is provided by University Hospitals Bristol and Weston NHS Foundation Trust coordinates SHFU across three counties (Avon & Somerset, Gloucestershire and Wiltshire) and refers on to GPs, paediatric and sexual health clinics. A baseline audit of the service showed 1 in 5 of 200 CYP each year did not attend SHFU with informal feedback highlighting difficult interactions including:-

*“she’s quite young, she doesn’t really understand what happened, she doesn’t really know the Bridge, she doesn’t know what an STI test is”*

*“she felt incredibly uncomfortable... in a normal local sexual health clinic”*

We found a service gap for survivors needing high quality, evidence-based sexual health and HIV care. We carried out an ambitious, trauma informed, co-production pathway re-design in which young survivors were placed at the centre, guided by psychological expertise in sexual violence and sexual health patient and public involvement <sup>3,4</sup>.

### How was change implemented?

We asked young survivors, their carers and professionals getting referrals about their lived experience of the current pathway. Ethical guidance was rigorously followed <sup>5</sup> but as service development, did not meet criteria for ethics committee scrutiny.

#### Patient and Public Involvement (PPI)

The work was entirely PPI in nature as a co-production project. Led through a partnership of clinical staff, young survivors from the voice group and the Greenhouse CSA support charity, Bristol.

We explored what might make our pathway better and the role of self-care/testing through,

- Creative workshops with the voice group, 3 CYP survivors aged 16-18
- Semi-structured interviews with 2 parents
- Focus groups with 20 professionals

The Greenhouse support service for survivors of childhood sexual abuse provided a safety net of support during and beyond the project as we recognised the ongoing burden of trauma. We asked to work with the voice group on their terms, on their territory and at their pace, we did not invite them into healthcare structures or procedures. We worked exclusively with young people in the post-therapy stage of recovery, alongside their trusted ‘voice’ worker.

We developed creative workshops based on evidence-based tools around consulting young sexual abuse survivors <sup>6</sup> and paid attention to power dynamics at every stage of the process <sup>7,8</sup>. Two clinical service providers lead alongside the voice group worker as it was important that the people in the conversation were the ones delivering the service. They engaged young survivors, not as patients but as experts in their own experience (after training and supervision from the health psychologist). Art and emojis were used to develop characters needing to use the service (Fig.1), allowing safe

distancing from the participants' own previous trauma. An example character and their lived context is pictured below.

Figure 1 – Workshop character

### What did we learn?

The three streams of qualitative engagement data (CYP, carers, staff) were translated into key issues of 1) choice, control and confusion, 2) how vs what was done and 3) carers/professionals needs. Young survivors felt confused, not knowing what was happening or why. This was compounded by lack of choice which mirrored some aspects of trauma. Trauma informed practice should attempt to re-instate control<sup>9</sup>. Many wanted to ask questions outside appointments or later.

The project co-produced a 'My Healthy Journey' map using clear, child friendly language/visuals with links to video guides to locations and procedures (Fig.2 – right). The document was both information but also the basis for the young survivor to shape their care including where they attended (including self-testing), who they felt safe with, who they could get advice from and what made them feel safe in different settings (familiar people, comfort items etc). Data from the young survivor 'characters' helped us understand how self-testing might work, for example 'Angel' felt home was not safe enough,

"Angel, "Her dad works from home... he checks her phone...so she'd have to hide it" [the test kit].

Questions could be texted to a 'your health after CSE' helpline/textline held by a clinical team member to provide live responses. For carers, the map enabled them to understand the process and guide their child, restoring some of their ability to protect and care which they reported being lost.

For the team, the essence of the work was not what changes were made but how the pathway gave decisions back to the young people whenever and wherever possible, constructing self-care as maximising their agency.

Professionals information needs and were addressed through trauma informed guidelines in a parallel 'staff' map (Fig.2, left) as well as a 'What CYP need from SHFU' training webinar.

Figure 2 – Pathway map

### What outcomes resulted from the change in practice?

Changes to the pathway were finely tuned with the co-production group to actively build perceptions of their own agency. Informal evaluation feedback was really positive, 'amazing'.. 'really proud' and "the group were really pleased with the outcomes...especially the way that what they had said got taken in and fed back...they have repeatedly said is what makes being part of the group worthwhile" (Voice facilitator).

### What are the next steps

Formal evaluation of both the new pathway and the co-production approach has started by asking the voice group how they would like the experience of co-production evaluated with a repeat audit and qualitative follow-up study to explore how CYP feel this helped or cost them. Bristol Health Partners and University Hospitals Bristol NHS Foundation have extended original funding to the evaluation. No competing interests exist.

### Key Messages

- 1) Self-care here meant maximising the service users' agency in shaping their own care including self-testing.
- 2) Co-production avoided bringing patients into healthcare structures/processes which hoards power but worked where they felt comfortable and supported.
- 3) Transformation was achieved in a trauma informed 'My Healthy Journey' map for patients to understand and control elements of their own care.

## References

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