

# BMJ Open Top 10 priorities for Sexual Violence and Abuse Research: findings of the James Lind Alliance Sexual Violence Priority Setting Partnership

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## ABSTRACT

**Objectives** To establish a James Lind Alliance (JLA) Priority Setting Partnership (PSP) to identify research priorities relevant to the health and social care needs of adults with lived experience of recent and/or historical sexual violence/abuse.

**Participants** Adults (aged 18+ years) with lived experience of sexual violence/abuse (ie, 'survivors') were consulted for this PSP, alongside healthcare and social care professionals who support survivors across the public, voluntary, community, independent practice and social enterprise sectors.

**Methods** In line with standard JLA PSP methodology, participants completed an initial online survey to propose research questions relevant to the health and social care needs of survivors. Research questions unanswered by current evidence were identified, and a second online survey was deployed to identify respondents' priorities from this list. Questions prioritised through the second survey were presented at a consensus meeting with key stakeholders to agree the top 10 research priorities using a modified nominal group technique approach.

**Results** 223 participants (54% survivors) provided 484 suggested questions. Seventy-five unique questions unanswered by research were identified and subsequently ranked by 343 participants (60% survivors). A consensus meeting with 31 stakeholders (42% survivors) examined the top-ranking priorities from the second survey and agreed the top 10 research priorities. These included research into forms of support and recovery outcomes valued by survivors, how to best support people of colour/black, Asian and minority ethnic and lesbian, gay, bisexual, transgender, and queer (LGBTQ+) survivors, improving access to high-quality psychological therapies, reducing public misconceptions/stigma, the impact of involvement in the criminal justice system on well-being, and how physical and mental health services can become more 'trauma informed'.

**Conclusions** These research priorities identify crucial gaps in the existing evidence to better support adult survivors of sexual violence and abuse. Researchers and

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first Priority Setting Partnership (PSP) to co-produce research priorities involving both individuals with lived experience of sexual violence and the health and social care professionals who support them.
- ⇒ The project followed a well-established methodology for identifying evidential uncertainties and research priorities in applied health research (the James Lind Alliance approach).
- ⇒ The PSP specifically took steps to increase involvement of groups that are often overlooked in this research area, such as LGBTQ+, people of colour/black, Asian and minority ethnic groups, and male survivors.
- ⇒ Due to the COVID-19 pandemic, the project only employed online methods to gather uncertainties and involve stakeholders.
- ⇒ Participation in this PSP was predominantly from stakeholders based in England, with less representation from other UK regions (and none internationally), overall reflecting the relative population size of different UK regions.

fundors should prioritise further work in these priority areas identified by survivors and the professionals who support them.

## INTRODUCTION

The prevalence and impacts of sexual violence and abuse (terms used interchangeably here to indicate any form of unwanted sexual activity or experience that is not consented to or is imposed, coerced or forced onto a person<sup>1</sup>) are widespread problems worldwide. International surveys suggest that exposure to sexual violence and abuse is endemic within both high and low/middle-income

countries, with approximately 1 in 10 women reporting lifetime exposure to sexual assaults.<sup>2</sup> Risk of exposure is considerably and consistently higher among women. However, anyone can be exposed to sexual abuse, and a sizeable minority of males are affected. In the UK, it has been estimated that approximately 20% of women and 4% of men experienced some form of sexual violence from the age of 16 years.<sup>3</sup> Estimates of the prevalence of childhood sexual abuse are similarly high. An English national household survey revealed that approximately 7.5% of females and 4.5% males had been exposed to various forms of sexual abuse before the age of 18 years,<sup>4</sup> and more recent national crime surveys suggesting that up to 7.5% of English and Welsh adults may have a history of childhood sexual abuse.<sup>5</sup> The above figures, however, might underestimate the magnitude of the problem, given the known barriers to sexual abuse disclosure. These include among others, shame, guilt, embarrassment, concerns surrounding confidentiality, fear of stigma, desire to protect friends and family and the concern of not being believed.<sup>6–8</sup> Factors relevant to specific groups of individuals with lived experience of sexual violence (ie, ‘survivors’) such as their gender identity, sexual orientation, ethnic and cultural background, disability and older age status may also exacerbate under-reporting.<sup>9–12</sup>

Extensive research has linked sexual abuse to potentially debilitating physical and mental health sequelae. Sexual abuse can induce a range of adverse physical health impacts in the immediate aftermath of an assault (including, among others, sexually transmitted infections, pregnancy and abortions, abrasions, lacerations and bruising<sup>13–15</sup>) and also increase the risk of longer-term, aggregated health complaints (including, for example, gynaecological and gastrointestinal problems, obesity, disruptions in sleeping patterns, chronic pain and fatigue<sup>14–18</sup>). Both short-term and long-term mental health impacts are well documented, with evidence confirming that people with lived experience of sexual abuse (here referred as ‘survivors’ for brevity, while acknowledging that the term may not capture the preferences and experiences of all individuals affected by sexual violence or abuse) are at increased risk of a wide range of mental health difficulties. These mental health difficulties can include, among others, depression, anxiety, post-traumatic stress disorder (PTSD), suicidality, self-harm, eating disorders, alcohol and drug misuse, impulsive behaviours, difficulties developing and maintaining close relationships, personality disorders, psychotic symptoms and medically unexplained symptoms.<sup>19–22</sup>

Despite the above findings, sexual violence remains an under-researched area.<sup>23</sup> This is especially true in relation to applied research that could address the multifaceted needs of survivors. Evidence suggests that there are considerable uncertainties (ie, questions that have not been fully answered by past high-quality research) around the management of the medical sequelae of sexual violence, including the reduction of barriers to the access to, and successful completion of, certain medical

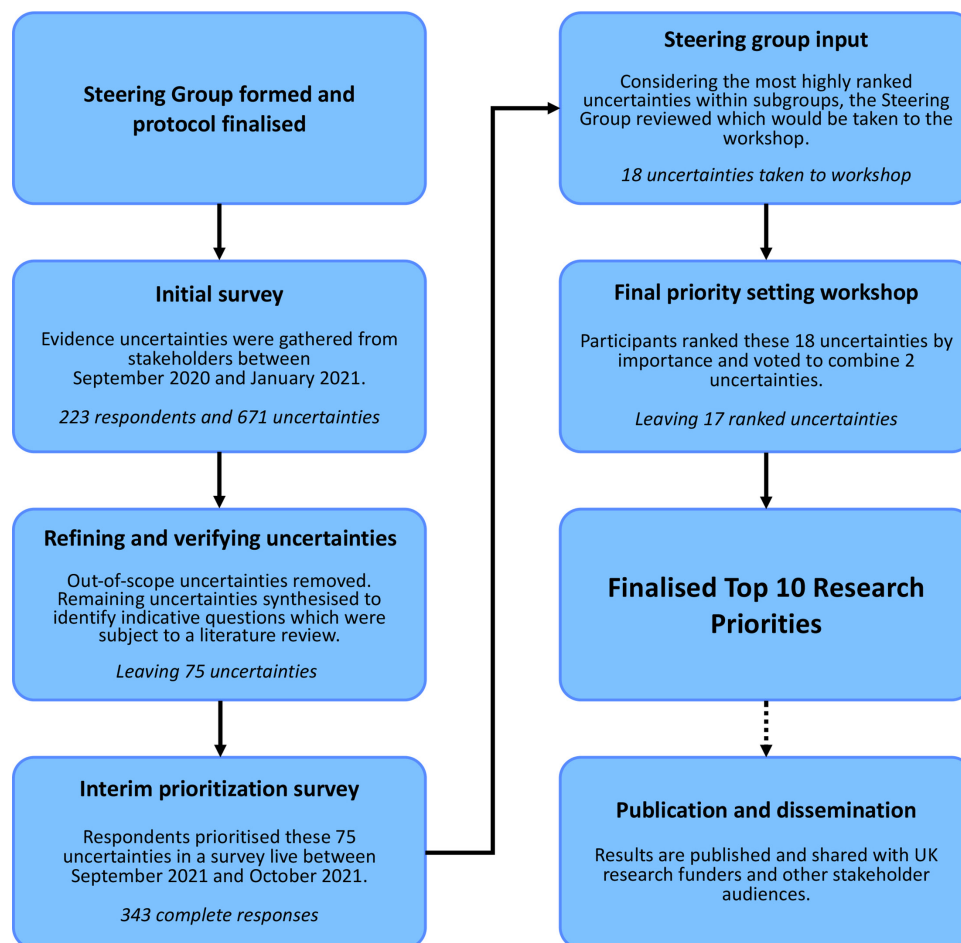
treatments addressing its physical health impacts as well as other health complaints.<sup>24–25</sup> Similarly, while there is convincing evidence for the efficacy of psychological interventions for PTSD in survivors of sexual violence,<sup>26</sup> there is a paucity of research on the efficacy of psychosocial interventions addressing the broader spectrum of mental health and well-being needs of survivors. Recent reviews have highlighted that there are still many unanswered questions around interventions for the physical and psychological consequences of sexual violence, and that people with lived experience should be the prime focus to develop novel, effective interventions.<sup>22</sup> The identification of research priorities around the support and recovery needs of survivors is therefore urgently needed to drive future investigations, service improvements and bespoke clinical guidelines.

With the growing recognition of the importance of meaningful Patient and Public Involvement and Engagement across all stages of health research, it is pivotal that future research is driven by the expertise, views, values, and priorities of people with lived experience of sexual violence and other ‘key stakeholders’ involved in the provision of services and support for survivors. Survivors, however, are rarely involved in shaping, conducting and disseminating research relevant to their needs.<sup>27</sup> The James Lind Alliance (JLA) is a UK non-profit initiative that has pioneered a transparent and well-established approach to bring individuals with lived experience, clinicians and other stakeholders together in ‘Priority Setting Partnerships’ (PSPs) designed to identify evidential uncertainties across a wide range of health topics. In the current project, we conducted the first JLA PSP specifically focused on the needs of adult survivors of sexual violence and abuse. The Sexual Violence Priority Setting Partnership (SVSP) aimed to consult and involve survivors and the professionals who support them across a range of settings, services and sectors. More specifically, the project aimed to identify uncertainties about the best way to support people with lived experience of sexual violence and to prioritise, by consensus, a list of the top 10 uncertainties that can promote future research by addressing the questions that key stakeholders consider to be most important.

## METHOD

### The JLA approach

The SVSP followed the standard priority setting methodology used by the JLA, as outlined in the JLA Guidebook.<sup>28</sup> In brief, the JLA approach involves five key stages: (1) a ‘project set-up’ stage, involving convening a Steering Group of stakeholder representatives to ratify the scope and protocol of the PSP and to guide all subsequent project activities; (2) a ‘gathering uncertainties’ phase, involving an initial survey to harvest evidential uncertainties from in-scope stakeholders (in this case, adults with lived experience of sexual violence/abuse and the healthcare, social care and third sector professionals



**Figure 1** A flow chart to display the JLA priority setting partnership process.

who support survivors in a professional capacity); (3) a ‘data processing and uncertainties verification’ phase, involving the systematic analysis of initial survey responses to identify questions unanswered by recent, high-quality research; (4) an ‘interim prioritisation’ phase, involving a second survey to rank unanswered uncertainties; and (5) a final consensus meeting with key stakeholder representatives to agree the top 10 unanswered research questions using a modified nominal group methodology. **Figure 1** displays the JLA processes followed by the SVPSP.

### Patient and Public Involvement and Engagement

In line with the JLA approach, the SVPSP involved extensive engagement with ‘experts-by-experience’ and ‘experts-by-profession’ in each step of the process, including via their active participation in the Steering Group, contribution to the development and ratification of the PSP protocol, the design of the initial and interim surveys, the analysis and interpretation of survey data, and participation in the final priority setting consensus workshop. Various organisations across the UK representing and advocating for key stakeholders relevant to this PSP (charities, support groups or professional organisations involved in supporting survivors) were approached at the onset of the project to establish a Steering Group to represent a diverse range of perspectives and groups,

including ‘seldom heard’ stakeholders such as individuals who identify as male, those belonging to sexual or ethnic minorities, and survivors from particularly vulnerable groups (eg, those with intellectual disabilities). Over the course of the project, 18 individuals contributed to the SVPSP Steering Group, including 9 individuals with lived experience of sexual violence/abuse (of which 7 had a professional background that involved at least some contact with survivors in health, social care or third sector settings) and 9 professionals. Representatives from the Steering Group are involved in all dissemination activities linked to this PSP, and several are coauthors of the present report.

### Protocol and scope of the PSP

The protocol<sup>29</sup> and scope of the PSP were decided upon at the first Steering Group meeting in March 2020.<sup>28</sup> The PSP scope was defined as the health and social care needs of adults (aged 18 years and over) currently living in the UK who have experienced any form of sexual violence or abuse, including penetrative and/or non-penetrative abuse at any point of their lives (including childhood). Questions related to the primary prevention of sexual violence or the criminal justice proceedings in response to sexual violence incidents (not including the impacts of involvement with the criminal justice system on the

well-being and needs of person) were regarded as out-of-scope for this PSP. In-scope stakeholders were (1) survivors and (2) health and social care professionals with current or previous experience of directly supporting UK survivors across the public, voluntary, community and social enterprise sectors. Professionals who also had lived experience of sexual violence (ie, referred here as ‘professionals with lived experience’) were regarded as in-scope. Any individuals who were not survivors or professionals were regarded as out-of-scope. Furthermore, despite recognising that the views and needs of individuals who identified solely as family members, supporters or loved ones of survivors are important, these were regarded to be likely distinct from those of survivors and were therefore regarded as out-of-scope for this specific PSP.

### Initial survey to collect uncertainties

Individuals living in the UK who identified as a survivor, a professional or a professional with lived experience completed an initial online survey for collecting uncertainties between September 2020 and January 2021. The survey was shared and advertised on various platforms (eg, via Saint Mary’s Sexual Assault Referral Centre (SARC) Instagram, Facebook and Twitter accounts) and by approaching Rape Crisis teams, SARCs and organisations representing and advocating for key stakeholders across the UK. After confirming their eligibility for this PSP, participants were asked to provide up to three questions they wanted future research to answer about the care, needs and support of adult survivors of unwanted sexual experiences. Responses to additional questions capturing key demographic characteristics of respondents (gender, ethnicity, sexuality, UK region of residence, expertise and disability status) were regularly reviewed so that the promotion of the survey could target specific groups and thereby increase the diversity of the perspectives gathered through the initial survey.

### Refining and verifying evidence uncertainties

After the exclusion of out-of-scope responses, the proposed uncertainties were thematically analysed to create a smaller set of ‘indicative questions’ that would represent all submitted uncertainties. First, four members of the SVPSP team scrutinised each submitted question and grouped them according to common topics/themes expressed in the content of the question. Second, three Steering Group members reviewed each group of questions to ensure they were thematically homogeneous, reallocate certain questions to a more appropriate groups and propose the creation of new groups of questions addressing similar topics. Third, members of the SVPSP team produced initial drafts of the wording of indicative questions representing the submitted uncertainties within each group. The wording of the indicative questions was then scrutinised, amended and ratified at Steering Group meetings to ensure they accurately represented the initial submitted uncertainties (ie, by comparing the

original submitted questions against their corresponding proposed indicative questions).

To determine if the indicative questions had already been answered by past research, a literature search was conducted to identify relevant systematic reviews and meta-analyses published in the previous 3years. The searches were undertaken by a Manchester University Foundation Trust librarian in November 2020 and updated in August 2021 on multiple databases (Medline, CINAHL and PsycINFO), using a search string comprising combinations of relevant search terms (sexual violence OR sexual abuse OR sexual exploitation OR rape OR sexual assault). Results of database searches were screened by four members of the team to identify reviews relevant to this PSP. The searches were supplemented by a manual search of relevant UK clinical guidelines (National Institute for Health and Care Excellence [NICE] guidelines) and the Cochrane Database of Systematic Reviews, both published in the previous 10 years. The identified pool of systematic reviews and meta-analysis was consulted to determine whether each indicative question was previously answered or partially answered by research. Questions that were fully answered by past research were not included in the subsequent interim survey.

### Interim prioritisation survey

In-scope stakeholders were invited to complete a second national survey between September and October 2021. The survey asked respondents to rank the unanswered indicative questions using a two-step process. First, respondents were presented with a randomly ordered list of all indicative questions and invited to select the questions most relevant to them, in order to create their own personalised shortlist. Second, respondents identified a maximum of 10 questions out of this shortlist. The survey was shared to relevant organisations and promoted both on social media and through the Steering Group networks. Again, demographic information collected as part of the survey was reviewed weekly to guide targeted promotion to specific under-represented groups (eg, via contacting professional organisations which specialised in the support of specific survivor groups).

The JLA’s guidance on online final consensus workshops sets a limit of 18 questions that can be brought forward for final prioritisation. To select questions to be brought forward to the final consensus meeting, the Steering Group reviewed the seven most endorsed questions by each of the three principal interim survey respondent groups (ie, survivors, professionals and professionals with lived experience). To ensure that the list was representative of the priorities of relevant minority groups, the Steering Group also reviewed the three most endorsed questions in each of the more specific respondent groups (males, ethnic minority groups, LGBTQ+ and individuals identifying as having a disability).

## Final consensus workshop

Thirty-one participants (a mix of survivors, professionals and professionals with lived experience, as well as a range of ages, genders, sexualities and ethnicities) were invited to the online workshop in November 2021. Participants were recruited from our Steering Group members, their networks (eg, professional organisations or survivor groups) or from interim survey respondents who had declared interest in taking part. The consensus building process used at the workshop draws on the principles of the nominal group technique<sup>30</sup> to allow all participants to adequately voice their opinions without discussion being dominated by specific individuals. Prior to the workshop, all participants individually ranked the 18 questions selected by the Steering Group. At the workshop, participants were separated into four smaller groups, each chaired by an independent JLA facilitator. Participants were first asked to share their top three and bottom three questions and the rationale for their personal rankings. Participants then collaboratively ranked each of the 18 questions as a group. After the rankings of the four groups had been aggregated into a combined ranking by the JLA facilitators, participants were divided into four new groups and reviewed the aggregated rankings. They then reranked the questions within each group, and the aggregation of these second small group rankings produced the final top 10 priorities. These were presented to all workshop attendees in a plenary session chaired by a JLA facilitator, giving participants a final chance to dispute rankings and reach consensus via a vote. Survivors and professionals with lived experience were offered a £100 thank you voucher for their time.

Several measures were taken to ensure the safety and confidentiality of participants at the workshop. Ahead of the workshop, all participants agreed to comply with strict confidentiality requirements; they were also provided with technical assistance to set a pseudonym on the online platform if they preferred to remain anonymous and were given the opportunity to be allocated to a female-only discussion group. A clinical psychologist and a researcher with extensive experience of working with survivors were available throughout the day to provide support to workshop attendees, should anyone find some of the topics discussed distressing.

## RESULTS

### Initial survey results

This initial survey was accessed by 675 individuals; however, 320 individuals left no responses. In total, 671 uncertainties were submitted by 223 respondents (132 respondents left only out-of-scope uncertainties). Of those who did leave relevant questions, 54% (n=121) identified as survivors, 16% (n=36) as professionals and 30% (n=66) as professionals with lived experience. Demographic data of respondents are shown in table 1.

After removing 187 out-of-scope responses, the remaining 484 proposed uncertainties were categorised

**Table 1** Demographic characteristics of in-scope initial survey responses and interim survey respondents

Expertise	Initial survey		Interim survey	
	n	%	n	%
Survivors	121	54.3	207	60.3
Professionals	36	16.1	47	13.7
Professionals with lived experience	66	29.6	89	26.0
<b>Gender</b>				
Male	21	9.4	35	10.2
Female	182	81.6	275	80.2
Non-binary	9	4.0	20	5.8
Prefer own term	7	3.1	5	1.5
Prefer not to say	4	1.9	8	2.3
Transgender*	11	4.9	18	5.2
<b>Age</b>				
18–24	21	9.4	39	11.4
25–34	50	22.4	95	27.7
35–44	49	22.0	72	21.0
45–54	61	27.4	64	18.7
55–64	33	14.8	57	16.6
65+	6	2.7	16	4.6
Did not answer	3	1.3		
<b>Ethnicity</b>				
White	194	87.0	310	90.4
Asian/British	3	1.4	6	1.8
Black/British	3	1.4	5	1.4
Mixed race	7	3.1	7	2.0
Other	7	3.1	4	1.2
Prefer not to say	9	4.0	11	3.2
<b>Sexuality</b>				
Heterosexual/straight	129	57.9	207	60.4
Bisexual	42	18.8	60	17.5
Lesbian	9	4.0	7	2.0
Gay	21	9.5	19	5.5
Prefer own term	13	5.8	25	7.3
Prefer not to say	9	4.0	25	7.3
<b>Country of residence</b>				
England	151	67.7	290	84.6
Northern Ireland	2	0.9	7	2.0
Scotland	18	8.1	16	4.7
Wales	12	5.4	20	5.8
Outside UK	4	1.8	2	0.6
Did not answer	36	16.1	8	2.3
<b>Disability</b>				
Any disability	60	26.9	108	31.5
Mental	26	11.7	32	9.3
Physical	9	4.0	26	7.6
Both	10	4.5	48	14.0
Did not specify	15	6.7	2	0.6

\*This response was not mutually exclusive with other response options for gender.

into 79 indicative questions (see online supplemental material 1). These covered all themes raised by the original submitted uncertainties and were worded to be clearer, possible research questions. The indicative questions were systematically contrasted against the findings of 174 recent systematic reviews and meta-analyses identified in our literature searches. These included 165 relevant publications (out of 1852 results of the original database search), 6 NICE guidelines and 3 Cochrane Reviews. Ultimately, four indicative questions were excluded due to being answered by past research. The questions pertained to (1) what interventions are most effective for reducing post-traumatic symptoms among survivors of sexual violence/abuse, (2) the relationship between experiencing sexual violence/abuse and having addiction issues, (3) whether exposure to sexual violence/abuse leads to short-term and/or long-term mental health problems other than PTSD, and (4) the relationship between experiencing sexual violence/abuse and having eating disorders and/or obesity.

### Interim prioritisation

The interim prioritisation survey received 668 responses. A sample of 343 respondents (51.3%) completed the survey in full; 60.3% (n=207) of received responses were from survivors of sexual violence/abuse, 13.7% (n=47) from professionals and 26.0% (n=89) from professionals with lived experience. Further information regarding the demographics of respondents is shown in [table 1](#). Online supplemental material 2 shows the most ranked questions for each considered subgroup (survivors, professionals, professionals with lived experience and relevant minority groups) that were reviewed by the Steering Group to identify the 18 questions to be brought forward for final prioritisation. The list of questions selected by the Steering Group is displayed in online supplemental material 3.

### Final consensus workshop

Thirteen survivors, 2 health/social care professionals and sixteen professionals with lived experience attended the final workshop. Before rankings were finalised, a vote was conducted to merge two thematically related questions concerning how physical healthcare and mental health services could become more 'trauma informed' (see questions ranked as '7' in online supplemental material 3). [Table 2](#) shows the final top 10 uncertainties that were agreed by all attendees as the most important unanswered research questions.

### DISCUSSION

The SVPSP collected 484 proposed uncertainties from 223 participants, which were systematically refined into 75 indicative questions/uncertainties that were not fully answered by previous research. These indicative questions were ranked by 343 in-scope participants, and 18 uncertainties reflecting the most highly ranked questions across multiple key groups (survivors, professionals, professionals with lived experience and relevant minority groups) were taken to a final consensus workshop for prioritisation. The top 10 uncertainties agreed at the final PSP workshop represent priority areas for future research to ensure funders and the academic community can design and deliver research consistent with the values and priorities of those directly affected by sexual violence and abuse.

The priorities identified by this PSP reflect several linked themes. Multiple identified uncertainties concerned, which forms of support and outcomes, are most valued by survivors themselves. The first research priority (see P1 in [table 2](#)), regarding what is seen as valued recovery outcomes by survivors, parallels findings from other areas of health research suggesting that people with lived experience do not necessarily value a

**Table 2** The top 10 priorities for sexual violence and abuse research

P1	From the perspective of survivors of sexual violence/abuse, what does recovery involve, what outcomes do they value and what factors can promote these outcomes?
P2	How can survivors of sexual violence/abuse who identify as people of colour or as members of black, Asian and minority ethnic groups be best supported?
P3	How can access to high-quality psychological therapies for survivors of sexual violence/abuse be improved?
P4	What interventions with the general public could reduce misconceptions and stigmas about sexual violence/abuse and their consequences on survivors of sexual violence/abuse?
P5	How can the process of police reporting and police investigation best support survivors of sexual violence/abuse and avoid retraumatisation, distress and victim-blaming attitudes?
P6	What support is most helpful to and valued by survivors of sexual violence/abuse themselves?
P7	How can mental health services and physical healthcare services that are likely to come into contact with survivors of sexual violence/abuse (for example, dental care, general practice, accident and emergency, intimate healthcare and pregnancy termination settings) become more 'trauma informed' to best support survivors and prevent retraumatisation?
P8	How does involvement in the criminal justice system impact survivors of sexual violence/abuse (for example, their emotional and psychological well-being), and what support do they need during and in the aftermath of criminal justice proceedings?
P9	How can support be more accessible, inclusive and effective for survivors of sexual violence/abuse who identify as LGBTQ+?
P10	How can survivors of sexual violence/abuse be supported to report sexual violence/abuse that happened many years ago, and what services should be offered to help them recover?

strictly clinical conceptualisation of recovery (ie, the absence of symptoms). For example, several studies have shown that people with lived experience of severe mental health difficulties (eg, psychosis, bipolar disorder) view recovery as a more complex and multifaceted phenomenon encompassing, for example, improved self-esteem, ability to sustain important personal relationships and improved quality of life regardless of ongoing 'symptoms'.<sup>31 32</sup> In turn, this research informed the development of measures of 'personal recovery' more aligned to the views and values of people with lived experience.<sup>33</sup> Research to explore what the construct of recovery means to different survivors, and the subsequent co-production of valid recovery measures aligned with their views, could benefit this research area and the future evaluation of recovery-promoting interventions. The uncertainty relating to the forms of support most useful and valued by survivors (P6) similarly highlights a potential mismatch between current service provision and the needs and preferences of those impacted by sexual violence. This relates to the frequent complaints in relation to the lack of access to specialist care and the importance of support coming from understanding and non-judgemental professionals.<sup>34-36</sup> Evidence that some conventional treatments for mental health difficulties are not favoured by survivors of sexual violence<sup>37</sup> further highlights that research on survivors' preferred forms of support is warranted. A particularly evident gap in valued support identified from this PSP pertained to the needs of survivors of non-recent sexual abuse (P10), a population whose needs have been historically poorly served by mainstream services due to a range of barriers already identified in previous research.<sup>38</sup>

Other priorities identified by this PSP related to research addressing the support needs of specific survivor groups, most notably individuals belonging to people of colour/black, Asian and minority ethnic communities (P2) and LGBTQ+ individuals (P9), who may face specific challenges and barriers to receiving appropriate, acceptable or valued care. For example, research into individuals affected by intimate partner violence (which in many cases can involve sexual coercion or victimisation) suggests that LGBTQ+ survivors experience additional barriers as a result of concerns around the support they might receive from gender-binary services, limited understanding of LGBTQ+ abuse, stigma and other systemic inequities within support systems.<sup>39</sup> Similarly, many individuals who identify as belonging to ethnic minority groups also experience additional challenges. For example, a lack of culturally appropriate services has been identified as a possible explanation for the low sexual violence reporting rates within British South Asian communities.<sup>10</sup> It should be noted that our Steering Group and the stakeholders consulted at the final workshop recommended that future research addressing the priorities identified by this PSP should be inclusive and responsive to the needs of minority groups more widely, beyond those specifically named in the above priorities. The data collected as part of this PSP suggest that, for

several indicative questions, there were marked differences in rankings among minority groups of interest (see online supplemental material 2). This consolidates past research which suggests these groups have specific needs and that it would be valuable for more specific, culturally appropriate or tailored support to be developed and evaluated.<sup>40</sup>

Other priorities reflect the importance of addressing the needs of survivors at a broader organisational, systemic and societal level. The priority concerning how mental and physical health services can become more trauma informed (P7) resonates with national initiatives to implement trauma-informed approaches across healthcare services, such as the UK's National Health Service (NHS) Long Term Plan<sup>41</sup> and the NHS England strategic direction for sexual assault and abuse services.<sup>42</sup> Although trauma-informed care is already highlighted in these national policies, more research is needed into its impacts and how it can be best implemented into health services and organisations, particularly for adult survivors of sexual violence. For example, systematic reviews conducted as part of the NICE guidelines for PTSD<sup>26</sup> identified a specific lack of high-quality evaluations of trauma-informed care. A closely related priority that could further improve a survivor's life-long care journey is increasing the availability of high-quality psychological interventions for survivors (P3; often regarded as a prerequisite for a truly trauma-informed service or organisation). While there is a strong evidence base for the efficacy of psychological interventions to improve PTSD across trauma survivors,<sup>43</sup> several respondents to our initial survey highlighted this area as a proposed priority (see online supplemental material 1), which suggests a potential lack of awareness or access to these treatments for many survivors. It should be noted that a range of people impacted by PTSD have discrete needs that may preclude them from receiving appropriate trauma-focused therapy as part of their routine care. For example, the presence of comorbid severe mental health difficulties (eg, psychosis) or addiction problems have been used as common exclusion criteria in PTSD clinical trials,<sup>44</sup> and similar criteria are often applied by mainstream services. Many survivors of sexual trauma may struggle with these comorbid difficulties, as well as with more pervasive post-traumatic symptoms consistent with the recently recognised International Classification of Diseases 11th Revision (ICD-11) diagnosis of 'Complex PTSD', for which there are currently no recommended evidence-based treatments.<sup>26</sup> These gaps in the evidence-based and linked treatment provision for survivors with complex mental health presentations are already recognised research priorities in several NICE guidelines.<sup>26 45</sup> In addition to research addressing the above NICE-recommended priorities, our PSP suggests that further implementation research to improve the availability of trauma-focused therapies and other high-quality psychological interventions that could address the multifaceted needs of survivors is particularly warranted.

At a broader societal level, stakeholders recommended the prioritisation of research into effective systems to reduce stigma and other harmful misconceptions about sexual abuse across society (P4). These stigma and misconceptions, ranging from group-specific ‘rape myths’ (eg, that males cannot be abused<sup>46</sup>) to broad victim-blaming messages and negative reactions to disclosed abuse,<sup>8</sup> not only impact the mental health and well-being of survivors (eg, by increasing self-blame), but represent important barriers to abuse reporting and help-seeking, which might exacerbate risk of revictimisation.<sup>7</sup> Evidence-based initiatives which seek to challenge damaging community attitudes towards survivors, informed by insights and methods gathered from past research to evaluate successful and unsuccessful anti-stigma programmes (eg, mental health stigma reduction initiatives<sup>47 48</sup>), are therefore urgently needed.

A final set of priorities pertained to addressing the potential impacts of involvement in criminal justice proceedings, including the process of police reporting and investigations, on the well-being of survivors (P5 and P8). These priorities corroborate past research suggesting that many survivors experience their contact with the criminal justice system as harmful and unsatisfactory, and in some cases even more harmful than the assault/abuse itself.<sup>49</sup> For some individuals, involvement with the criminal justice system is associated with retraumatisation and ‘secondary victimisation’; that is, exposure to insensitive or victim-blaming practices and negative survivor experiences at various stages of contact with the police and the justice system that can result in greater traumatisation.<sup>50 51</sup> These dynamics are likely to disproportionately affect groups of survivors exposed to multiple inequalities (eg, racial, gender based, etc<sup>52</sup>). These SVPSP priorities highlight the importance of ensuring that abuse reporting and investigations become more ‘survivor centred’ and trauma informed. For example, the development of evidence-based training designed to help reduce victim-blaming biases among police officers and other professionals involved in the legal system<sup>53</sup> may represent an important direction for future research in this area, as well as the development and evaluation of systems to provide survivors with adequate emotional and psychological support across all stages of their involvement in criminal justice proceedings.

To our knowledge, this is the first specific initiative to co-produce research priorities to address the varied impacts of sexual abuse using an established priority setting methodology. However, several caveats of our work should be kept in mind when evaluating the priorities identified by the SVPSP. First, the project was conducted during the COVID-19 pandemic, and therefore relied solely on online data collection methods. Despite efforts made by the SVPSP team to engage a wide range of stakeholders, this might have limited the breadth and diversity of the stakeholders we consulted, particularly individuals who might experience digital inequality. Second, the responses were predominantly from stakeholders in England (over

70%); however, this reflects the relative population size of different UK regions (ie, approximately 85% of the UK population lives in England). While the UK focus of this project, and indeed of most PSPs supported by the JLA, ensures that the identified priorities are highly relevant to stakeholders based in the UK, it is possible that the priorities of survivors and professionals based in other countries may differ from those identified by the SVPSP. Our priorities are broad and likely to be applicable to many survivors outside the UK; however, other initiatives may be conducted globally to examine the extent to which our top 10 priorities reflect those of stakeholders in other national contexts. Third, the scope of this PSP specifically focused on uncertainties relevant to the care of adult survivors. This decision was taken because of the likely distinct needs of young people impacted by sexual abuse, which might not have been sufficiently considered if examined in the context of the current PSP. A separate dedicated PSP for this population is therefore warranted. Similarly, we excluded from the SVPSP scope questions related to the primary prevention of sexual violence as well as those related to the technicalities of legal proceedings involved in sexual violence and abuse criminal cases. While such restrictions were necessary to ensure the project had sufficient focus to deliver meaningful priorities that related to our primary scope (the health and social care needs of survivors), the primary prevention of sexual violence/abuse and the needs of individuals at elevated risk of sexual victimisation and exploitation are undoubtedly important areas deserving further research and applied work. Similarly, the number of out-of-scope questions received as part of this PSP suggests there is a broader range of questions of interest to survivors and professionals, beyond those related to survivors’ health and social care needs. These could be examined by other targeted priority setting initiatives in the future.

To conclude, the final top 10 priorities of the SVPSP reflect aspects of sexual violence and abuse that have not been sufficiently scrutinised by past research. Beyond the top 10 priorities, the other evidential uncertainties identified through this PSP and listed in our supplemental materials would benefit from further research. Our findings indicate that only 5% of the questions proposed by stakeholders were fully answered by past research. While this might be a by-product of the stringent JLA criterion for classifying a research uncertainty as fully answered (ie, the presence of a recent and conclusive systematic review or meta-analysis on that specific topic), this finding suggests that much work is needed to answer research questions valued by key stakeholders in this area. In parallel, attempts should be made to develop evidence-based clinical guidelines for adult survivors of recent and/or non-recent sexual abuse. While dedicated NICE clinical guidelines for children exposed to abuse are already available,<sup>54</sup> no specific clinical guidelines for sexual violence and abuse in adults have been developed. A dedicated clinical guideline is therefore not only warranted but would represent an important conduit for



ensuring future effective translation of research findings into improved care for survivors across the UK.

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**Patient consent for publication** Not required.

**Ethics approval** As a project involving PPIE activities to inform future research, the SVPSP was regarded as not requiring approval from an ethics board following evaluation using the Health Research Authority and the University of Manchester Research Ethics decision tools, and consultations with the Research and Innovation departments of Greater Manchester Mental Health NHS Foundation Trust and Manchester University NHS Foundation Trust.

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#### REFERENCES

- 1 Gavey N, Violence S. *Teo T, ED. encyclopedia of critical psychology*. New York, NY: Springer, 2014: 1742–6.
- 2 Scott KM, Koenen KC, King A, *et al*. Post-Traumatic stress disorder associated with sexual assault among women in the who world mental health surveys. *Psychol Med* 2018;48:155–67.
- 3 Office of National Statistics. *Sexual offences in England and Wales: year ending March 2017*. UK: Office of National Statistics, 2017.
- 4 Bellis MA, Hughes K, Leckenby N, *et al*. National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC Med* 2014;12:72.
- 5 Office of National Statistics. *Child sexual abuse in England and Wales: year ending March 2019*. UK: Office of National Statistics, 2020.
- 6 Aakvaag HF, Thoresen S, Wentzel-Larsen T, *et al*. Broken and guilty since it happened: a population study of trauma-related shame and guilt after violence and sexual abuse. *J Affect Disord* 2016;204:16–23.
- 7 Miller AK, Canales EJ, Amacker AM, *et al*. Stigma-Threat motivated nondisclosure of sexual assault and sexual Revictimization. *Psychol Women Q* 2011;35:119–28.
- 8 Kennedy AC, Prock KA. "I Still Feel Like I Am Not Normal": A Review of the Role of Stigma and Stigmatization Among Female Survivors of Child Sexual Abuse, Sexual Assault, and Intimate Partner Violence. *Trauma Violence Abuse* 2018;19:512–27.
- 9 Harvey S, Mitchell M, Keeble J. *Barriers faced by lesbian, gay, bisexual and transgender people in accessing domestic abuse, Stalking, harassment and sexual violence services*. Cardiff, Wales: Welsh Government, 2014.
- 10 Harrison K, Gill AK. Breaking down barriers: recommendations for improving sexual abuse reporting rates in British South Asian communities. *Br J Criminol* 2018;58:273–90.
- 11 Rape Crisis Network Ireland. *Sexual violence against people with disabilities: data collection and barriers to disclosure handout*, 2012.
- 12 Majeed-Ariss R, Rodriguez PM, White C. The disproportionately high prevalence of learning disabilities amongst adults attending Saint

- Marys sexual assault referral centre. *J Appl Res Intellect Disabil* 2020;33:595–603.
- 13 Allsworth JE, Anand M, Redding CA, et al. Physical and sexual violence and incident sexually transmitted infections. *J Womens Health* 2009;18:529–34.
  - 14 Jina R, Thomas LS. Health consequences of sexual violence against women. *Best Pract Res Clin Obstet Gynaecol* 2013;27:15–26.
  - 15 Alempijevic D, Savić S, Pavlekic S, et al. Severity of injuries among sexual assault victims. *J Forensic Leg Med* 2007;14:266–9.
  - 16 Eby KK, Campbell JC, Sullivan CM, et al. Health effects of experiences of sexual violence for women with abusive partners. *Health Care Women Int* 1995;16:563–76.
  - 17 Steine IM, Harvey AG, Krystal JH, et al. Sleep disturbances in sexual abuse victims: a systematic review. *Sleep Med Rev* 2012;16:15–25.
  - 18 Paras ML, Murad MH, Chen LP, et al. Sexual abuse and lifetime diagnosis of somatic disorders: a systematic review and meta-analysis. *JAMA* 2009;302:550–61.
  - 19 Hailes HP, Yu R, Danese A, et al. Long-Term outcomes of childhood sexual abuse: an umbrella review. *Lancet Psychiatry* 2019;6:830–9.
  - 20 Campbell L, Keegan A, Cybulska B, et al. Prevalence of mental health problems and deliberate self-harm in complainants of sexual violence. *J Forensic Leg Med* 2007;14:75–8.
  - 21 Chen LP, Murad MH, Paras ML, et al. Sexual abuse and lifetime diagnosis of psychiatric disorders: systematic review and meta-analysis. *Mayo Clin Proc* 2010;85:618–29.
  - 22 Nelson S, Baldwin N, Taylor J. Mental health problems and medically unexplained physical symptoms in adult survivors of childhood sexual abuse: an integrative literature review. *J Psychiatr Ment Health Nurs* 2012;19:211–20.
  - 23 Sexual Violence Research Initiative. FAQ: sexual violence research initiative, 2019. Available: <https://www.svri.org/faq> [Accessed 25 Aug 2019].
  - 24 Schopper D. Responding to the needs of survivors of sexual violence: do we know what works? *International Review of the Red Cross* 2014;96:585–600.
  - 25 Fredriksen TV, Sjøftestad S, Kranstad V, et al. Preparing for attack and recovering from battle: understanding child sexual abuse survivors' experiences of dental treatment. *Community Dent Oral Epidemiol* 2020;48:317–27.
  - 26 NICE. *Post-Traumatic stress disorder: National Institute of health and care excellence*, 2018.
  - 27 Kennedy S, Bewley S, Chevoux J, et al. A systematic review that evaluates the extent and quality of involving childhood abuse survivors in shaping, conducting and disseminating research in the UK. *Research for All* 2022;6.
  - 28 The James Lind Alliance. *The James Lind alliance Guidebook*. UK: National Institute for Health Research, 2021.
  - 29 Varese F, Mohammed L, Majeed-Ariss R. Sexual violence PSP protocol, 2021. Available: <https://www.jla.nihr.ac.uk/documents/sexual-violence-ppsp-protocol/27114?pr=>
  - 30 Jones J, Hunter D. Consensus methods for medical and health services research. *BMJ* 1995;311:376–80.
  - 31 Law H, Morrison AP. Recovery in psychosis: a Delphi study with experts by experience. *Schizophr Bull* 2014;40:1347–55.
  - 32 Kraiss JT, Ten Klooster PM, Chrispijn M, et al. Measuring personal recovery in people with bipolar disorder and exploring its relationship with well-being and social role participation. *Clin Psychol Psychother* 2019;26:540–9.
  - 33 Neil ST, Kilbride M, Pitt L, et al. The questionnaire about the process of recovery (QPR): a measurement tool developed in collaboration with service users. *Psychosis* 2009;1:145–55.
  - 34 Yuan NP, Koss MP, Stone M. *The psychological consequences of sexual trauma*, 2006.
  - 35 Independent Inquiry into Child Sexual Abuse. *Support services for victims and survivors of child sexual abuse*. UK: University of Hertfordshire, 2020.
  - 36 Stefanidou T, Hughes E, Kester K, et al. The identification and treatment of mental health and substance misuse problems in sexual assault services: A systematic review. *PLoS One* 2020;15:e0231260..
  - 37 Barbe RP, Bridge JA, Birmaher B, et al. Lifetime history of sexual abuse, clinical presentation, and outcome in a clinical trial for adolescent depression. *J Clin Psychiatry* 2004;65:77–83.
  - 38 Havig K. The health care experiences of adult survivors of child sexual abuse: a systematic review of evidence on sensitive practice. *Trauma Violence Abuse* 2008;9:19–33.
  - 39 Calton JM, Cattaneo LB, Gebhard KT. Barriers to help seeking for Lesbian, gay, bisexual, transgender, and Queer survivors of intimate partner violence. *Trauma Violence Abuse* 2016;17:585–600.
  - 40 Coulter RWS, Mair C, Miller E, et al. Prevalence of Past-Year sexual assault victimization among undergraduate students: exploring differences by and intersections of gender identity, sexual identity, and Race/Ethnicity. *Prev Sci* 2017;18:726–36.
  - 41 NHS. *The NHS long term plan*, 2019.
  - 42 NHS England. *Strategic direction for sexual assault and abuse services*. UK, 2018.
  - 43 Bisson JI, Ehlers A, Matthews R, et al. Psychological treatments for chronic post-traumatic stress disorder. systematic review and meta-analysis. *Br J Psychiatry* 2007;190:97–104.
  - 44 Ronconi JM, Shiner B, Watts BV. Inclusion and exclusion criteria in randomized controlled trials of psychotherapy for PTSD. *J Psychiatr Pract* 2014;20:25–37.
  - 45 NICE. *Psychosis and schizophrenia in adults: prevention and management: National Institute of health and care excellence*, 2014.
  - 46 Hammond L, Ioannou M, Fewster M. Perceptions of male rape and sexual assault in a male sample from the United Kingdom: barriers to reporting and the impacts of victimization. *Journal of Investigative Psychology and Offender Profiling* 2016;14.
  - 47 Pinfold V, Thornicroft G, Huxley P, et al. Active ingredients in anti-stigma programmes in mental health. *Int Rev Psychiatry* 2005;17:123–31.
  - 48 Walsh DAB, Foster JLH. A call to action. A critical review of mental health related Anti-stigma campaigns. *Front Public Health* 2020;8:569539.
  - 49 Campbell R, Wasco SM, Ahrens CE. Preventing the “Second Rape”: Rape Survivors' Experiences With Community Service Providers. *J Interpers Violence* 2001;16:1239–59.
  - 50 Campbell R. Rape survivors' experiences with the legal and medical systems: do rape victim advocates make a difference? *Violence Against Women* 2006;12:30–45.
  - 51 Lorenz K, Kirkner A, Ullman SE. A qualitative study of sexual assault survivors' Post-Assault legal system experiences. *J Trauma Dissociation* 2019;20:263–87.
  - 52 Decker MR, Holliday CN, Hameeduddin Z, et al. “You Do Not Think of Me as a Human Being”: Race and Gender Inequities Intersect to Discourage Police Reporting of Violence against Women. *J Urban Health* 2019;96:772–83.
  - 53 Tidmarsh P, Hamilton G, Sharman SJ. Changing Police Officers' Attitudes in Sexual Offense Cases: A 12-Month Follow-Up Study. *Crim Justice Behav* 2020;47:1176–89.
  - 54 NICE. *Child abuse and neglect: National Institute of health and care excellence*, 2017.