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#### **Review Article**

**Title:** What are the experiences and the perceptions of service users attending Emergency Department for a mental health crisis? A systematic review.

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- 4. Drafting the article Maya Sacre
- 5. Critical revision of the article Juanita Hoe, Maya Sacre, Rikke Albert
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#### Abstract

Historically, dualistic healthcare systems have resulted in limited mental health care provision within physical health settings, with service users reporting poor care specifically while attending emergency departments in a mental health crisis. Modern approaches to healthcare recognise these inequalities and are moving toward integrating healthcare systems that allow more holistic and seamless experiences for service users. This mixedmethod review examines the experiences and perceptions of service users attending emergency departments for a mental health crisis. Systematic searches of eight databases on two platforms (EBSCO, OVID) and grey literature databases (Open Grey, Base) were conducted. Studies were systematically screened for inclusion based on predetermined eligibility criteria and quality assessed using the Mixed Methods Appraisal Tool. Findings were tabulated and synthesised using thematic synthesis. Ten studies consisting of qualitative and mixed-method designs were included in the review. Five overarching themes emerged from the synthesis: social constructs, service provider, service provision, effectiveness, and emotional impact. The findings from this review show that service users continue to have negative experiences in emergency departments due to stigmatising attitudes and low skill in managing mental health needs. Whereas more positive experiences are attributed to the availability of mental health liaison services. Tackling stigma, improving communication and staff training, providing calm environments, addressing structural issues that promote better interagency working and reduce gaps in services are needed to improve mental health service user experience. Future research should focus on trauma-informed approaches in emergency departments to improve person-centred care for service users experiencing a mental health crisis.

**Keywords**: Emergency Department, Mental health care, Mental health crisis, Patient experience, Stigma.

#### Introduction

Mental illness accounts for the largest burden of disease in the UK (Public Health England, 2018). Furthermore, people who have chronic mental illnesses are at risk of dying 15-20 years earlier due to physical health co-morbidities such as cardiovascular disease and diabetes (King's Fund, 2016). This is due in part, to receiving poorer physical healthcare, despite the evidence that anti-psychotics can increase the risk of metabolic and cardiovascular diseases, as well as lifestyle risks (WHO, 2008; King's Fund, 2016). Historically, healthcare systems divided themselves by physical and mental health care, with mental health care regarded as a specialism as opposed to traditional care. This divide has contributed to limited mental health care provision in physical health settings and vice versa (WHO, 2008; King's Fund, 2016). Poor recognition and management of common mental health problems in general hospitals results in longer stays, delayed discharge, inappropriate treatments and a cycle of returning service users (King's Fund, 2016). Achieving integrated care by providing a space whereby service users can have both their physical and mental health needs met effectively would improve health outcomes and experience for these populations, as well as contributing to the de-stigmatisation of mental illness (WHO, 2008; King's Fund, 2016; Carstensen et al., 2017; CQC, 2015). This will require both upskilling all staff to feel confident working with both physical and mental health, as well as increasing the availability of mental health facilities or teams in predominantly physical health settings and vice versa.

Modern approaches to healthcare recognise these gaps and inequalities. For example, in the UK, the NHS is moving toward integrating health and social care systems funding for care delivery to allow for a more holistic and seamless experience for the service users (MH Taskforce, 2016). This integrated approach is particularly important to respond to mental health crises in the Emergency Department (ED). Only half of the UK community mental health teams offer a 24/7 service and healthcare systems rely on the emergency services such as ambulance staff, the ED and police to support those requiring urgent care out of hours (MH Taskforce, 2016). However, dissatisfaction with out of hours support for mental health crises is evident. The ED was rated worst for service user experience in a mental health crisis, in comparison with support received from GP, police, charities, and telephone helplines (CQC, 2015). Only 14% of adults surveyed felt they had received the right response

whilst in crisis (MH Taskforce, 2016). Services users describe feeling "batted away" from receiving support when in a crisis (Paton et al., 2016). The key barriers identified include healthcare professionals' attitude, wait times, and not receiving sufficient information (Paton et al., 2016). In particular, people who self-harm report traumatic experiences in accessing care in the ED, such as being denied analgesia when suturing wounds (Paton et al., 2016).

Previous studies found that clinicians in general hospitals and specifically in the ED have a more negative attitude toward mental health service users when compared to mental health clinicians (Saunders et al., 2012; Clarke et al., 2014). For example, staff perceived service users with mental health conditions as manipulative, disingenuous, dangerous and unpredictable (Clarke et al., 2014). While other staff described a "why bother" attitude when working with this service user group due to the repeat attendances and lack of effective follow up care (Clarke et al., 2014). Low confidence and skills in managing this population impact on staff's attitudes (Clarke et al., 2014). When nurses felt competent, they were more likely to have positive attitudes toward their service users.

Mental health liaison teams in the UK consist of multi-disciplinary mental health professionals based in the acute hospitals (Baugh et al., 2020). These liaison teams assess and support service users attending ED for a mental health crisis. Best practice guidance in the UK recommends these teams offer training to ED staff about the impact of stigma, mental health awareness and risk management (Baugh et al., 2020). The Liaison model has been in existence for over two decades yet by 2016 only 16% of general hospitals across the UK had liaison teams that worked 24 hours a day (MH Taskforce, 2016). Currently, services vary in operating hours, provisions, and team structures (NHS England, 2016). Nonetheless, evidence shows that mental health liaison services in general hospitals are cost effective and decrease the length of stay for service users (NHS England, 2016; Wood & Wand, 2014; Pattinson & McCrae, 2017; Tadros et al., 2013). However, further evidence is required to demonstrate how these developments' impact on service user experience.

Alternative provisions have been set up to support people in mental health crisis. Crisis cafes offer people a safe place to go in a crisis, the ethos of such places tends to be collaborative care, respect, dignity and compassion (Paton et al., 2016). However, these settings are not set up to manage physical needs such as treatment for overdoses or self-

harm. Alternatives include specialised Psychiatric Emergency Services (PES) or Emergency Psychiatric Units (EPU) more commonly used in the US and Canada and initiated in England during the COVID pandemic. These tend to be affiliated with a general ED but may be on a separate campus (Zeller et al., 2014). Evidence shows the EPU models are cost effective, reduce length of stay, wait times and improve service user experience (Zeller et al., 2014; Ledet & Chatmon, 2019). However, the separate nature of EPUs and crisis cafes can reinforce the divided approach to healthcare.

## Rationale

NHS England's (2016) report on achieving better 24-hour mental health care advises that evaluation of current service provision is required to identify gaps. In particular, service user feedback is an essential part of improving services and adhering to person-centred care (NICE, 2011). This review aims to provide an overall picture of service user experience in ED for a mental health crisis, including those with or without specialist provision such as liaison teams. Carstensen et al., (2017) carried out a review on nine papers ranging from 2003-2016 to summarise service user experience in ED. They found that service user experience was largely negative. Given the emphasis of the NHS 'Five Year Forward View' plan on improved access to crisis care in the ED (MH Taskforce, 2016), an up-to-date review is needed to evaluate the impact on service user experience, yet no further reviews on this topic have been identified. Our review builds on the existing evidence and includes all ages and mental health service users with co-morbid substance use, and intellectual disabilities, which were excluded in the previous review. This review will contribute to ongoing evidence and inform guidance on service developments for mental health service users accessing ED in crisis. A mixed methods approach including both quantitative and qualitative data was undertaken to allow for greater insight into service user experiences.

#### **Aims**

This systematic review aimed to answer the following question: What are the experiences and the perceptions of service users attending ED for a mental health crisis? The objectives of the review being to examine the existing evidence and 1) To develop a better

understanding of service user experience in ED for a mental health crisis. 2) To identify key factors influencing negative and positive experiences. 3) To identify gaps in the evidence and make suggestions for future research. The findings are used to make recommendations for improving care experiences in ED for those in mental health crises.

#### Methods

## Search Strategy

Methods used for the systematic review are in accordance with the Cochrane handbook (Higgins et al., 2021) and reported in accordance with the PRISMA-P guidelines (Page et al., 2021). Search terms were formulated using Boolean operators based on the PEO (Population Exposure Outcome) as seen in Table 1. A typical example of a search is available in the supplementary data (Appendix I). Eight different databases were searched on 8<sup>th</sup> and 9<sup>th</sup> of January 2020 on two platforms: EBSCO (CINAHL, Medline, Health Policy Reference Centre, PsycINFO), OVID (AMED, Medline, HMIC, Ovid Nursing Database), selected for their relevance to the topic. Grey literature searches were conducted to reduce the risk of publication bias using "Open Grey" and "Base" databases (Petticrew & Roberts, 2008). In addition, The King's Fund website was hand searched under the service user experience section. Finally, "Web of Science" was used to undertake citation and reference tracking for certain key papers. A further search was conducted prior to submission of this review to confirm its relevance by exploring any new evidence related to this review.

#### Table 1: Search terms

#### Eligibility Criteria

All study designs were considered and included studies were identified as per the eligibility criteria shown in Table 2. Study populations included service users attending ED for a "mental health crisis". Due to ambiguity around what constitutes a mental health crisis, the following definition was used for this review: "that the person or anyone else believes requires immediate support" (NHS England, 2016). It was therefore assumed all those

attending ED for their mental health were requiring urgent care due to the nature of the setting. Reasons for attending were extended to: substance use, self-harm, suicidal ideation, anxiety, depression, psychosis. Participants attending the ED for reasons unrelated to mental health were excluded, regardless of whether they had an existing psychiatric history. No limitation was placed on age or gender of included populations.

The exposure encompassed all ED within general hospitals, including those with specialist mental health provision such as liaison teams. Specialist services such as EPUs and crisis houses that are separate to general hospitals were excluded as they are not aiming to meet physical healthcare needs and therefore, do not reflect the experience of an integrated service relevant to the objective of this review. Evaluations of specific mental health interventions within the ED were also excluded to ensure that the overall experiences of care in ED was reflected in the review as opposed to experiences of specific interventions or tools. Regarding outcome, only service user and carer's views were included, to ensure the focus of the review was service user specific. Papers not in the English language were excluded due to lack of resources for translation.

## Table 2: Eligibility Criteria

#### Study Selection

Study selection followed a two-stage process, firstly screening all papers via title and abstract, then reviewing full text articles for the remaining papers. Initially, 10% of the papers were screened by two reviewers (MS and AO) and disagreements were discussed to reduce bias in the screening process. An inter-rater reliability score (Cohen's Kappa) was obtained to measure level of agreement to ensure that risk of bias was low in study selection (Higgins et al., 2021). One researcher, (MS), screened the remainder of the papers at stage one. At stage two, MS screened all the papers using the full text and reasons for exclusion were recorded.

#### **Quality appraisal**

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The Mixed Method Appraisal Tool (MMAT) (Hong et al., 2018) was used to appraise the

quality of all the included papers. Using one tool across all studies allowed for better

comparison and consistency across all appraisals.

**Data Extraction & Synthesis** 

A bespoke form was created for data extraction and piloted before being finalised. Study

characteristics, demographics, patient satisfaction and themes were extracted from the

papers. Thematic analysis was used to synthesise the qualitative data extracted including

identified themes and satisfaction scores. This method was selected given the mid-range

thickness of data found and the lack of pre-existing theory on the topic (Noyes et al., 2018).

Extracted data were coded line by line and then organised into descriptive themes and

finally into analytical themes as per Thomas & Harden's (2008) thematic analysis methods.

Example quotes from the text reviewed are used to illustrate the themes identified.

Quantitative data were synthesised narratively due to the heterogeneity of the data

obtained, rendering a meta-analysis inappropriate.

**Results** 

The Prisma Flow diagram (Page et al., 2021) outlines the systematic search and screening

process (see Figure 1). The search yielded 2,813 papers, leaving 1,824 publications once

duplicates were removed. Papers were screened by title and abstract leaving 56

publications. The Inter-rater reliability score suggested "Good Agreement" (k = 0.627)

(Higgins et al., 2021). Full text screening of the 56 publications identified 10 eligible studies.

The reasons why studies were excluded are listed in Figure 1; for example, where settings

were an EPU or crisis house, or the population were general ED attendees.

Figure 1: PRISMA Flow Diagram

**Study Characteristics** 

The characteristics of the ten included papers are shown in Table 3 and referenced P1-P10 (Collom et al., 2019<sup>P1</sup>; Fleury et al., 2019<sup>P2</sup>; Harris et al., 2016<sup>P3</sup>; Harrison et al., 2015<sup>P4</sup>; Owens et al., 2016<sup>P5</sup>; Spassiani et al., 2017<sup>P6</sup>; Thomas et al., 2018<sup>P7</sup>; Vandyk et al., 2017<sup>P8</sup>; Wand et al., 2016<sup>P9</sup>; Wise-Harris et al., 2017<sup>P10</sup>). These papers were published between 2015 and 2019. Studies differed in aims but all explored service user experience in the ED for a mental health crisis. Five studies explored service user experience about a specific episode of attendance within a particular ED<sup>P4,P9</sup> or across a selection of EDs<sup>P1, P2, P10</sup>, while five explored service user's more general experiences about attending ED for mental health crises without specifying a timeframe<sup>P3, P5-8</sup>. Two studies explored a range of settings including both EDs and EPUs but make limited distinction between these in the results sections<sup>P2, P7</sup> and where possible data extracted from these papers is limited to service user experience in ED.

## Table 3: Study Characteristics of included papers

Five studies were based in Canada<sup>P2,P4,P6,P8,P10</sup> one in Australia<sup>P9</sup>, two in the US<sup>P3,P7</sup> and two in the UK<sup>P1,P5</sup>. The review encompasses data collected on 518 participants, which included specific populations such as "frequent attenders"<sup>P8,P10</sup>, service users with intellectual disabilities<sup>P6</sup>, young people who self-harm<sup>P3</sup>, and carers<sup>P1</sup>. There were 18 carers or family members, with the remaining participants all being service users. Half of the studies had a relatively even male to female ratio<sup>P2,P4,P8,P9,P10</sup>, with the remaining studies having more female participants. Ethnicity was inconsistently reported and where identified most participants were Caucasian. Ages across all studies ranged from 12-98 years, with the mean age being 40 years<sup>P2,P4,P9,P10</sup>. Certain papers fell as outliers to the normal range of age<sup>P1,P5</sup> due to their specific population sample.

Only two papers reported demographics regarding education, income and social status, showing high rates of unemployment<sup>P2</sup> and receipt of disability benefits<sup>P10</sup> amongst participants. However, many lived in their own homes<sup>P2</sup> and a small proportion had a history of homelessness in the last 12 months<sup>P10</sup>. Table 4 outlines the nature of the reasons reported for attendance and frequency of ED visits over one year. Some studies specified

provisions available within the ED for mental health care such as Mental Health Liaison Teams, P1,P9 while others did not P3,P5,P6,P8. Harrison et al P4 gathered perspectives from participants transferred from ED to a specialist EPU. Whereas Wand et al P9 focuses specifically on feedback about the Mental Health Liaison Nurse care delivery as part of the overall ED experience.

## Table 4: Reasons for attendance and number of visits

# Quality Appraisal and methodological critique of the included studies

The quality appraisal of included studies is shown in Table 5 and overall evaluation reported in Table 3. The relevant sections of the MMAT (Hong et al., 2018) are explained in appendix II. Most study designs demonstrated adequate levels of rigour and were of good quality, which allows the synthesis of data to be considered with some confidence. Two studies were rated weak due to poor reporting of data collection methods and analysis of results, P2,P4 and their data should be viewed with caution.

#### Table 5: Quality appraisal using MMAT

Sampling biases are particularly relevant in harder to reach populations as the nature and severity of mental health crises may leave some service users under-represented, which impact on the transferability of finding (Brink et al., 2018). Purposive sampling strategies<sup>P1,P3,P5-10</sup> were used in most studies to ensure selected participants met eligibility criteria. Convenience sampling was used in two further studies<sup>P2,P4</sup> but provides little opportunity to control bias (Brink et al., 2018). Fleury et al<sup>P2</sup> reduced the risk of bias by attending various EDs at different times of the day and week to recruit their sample. While Wise-Harris et al<sup>P10</sup> reduced sampling bias by identifying and delaying interviews for difficult to engage service users until the severity of their symptoms had reduced. Two further studies used secondary analyses of data already collected<sup>P3,P5</sup>, which reduces the burden on

marginalised groups who may be difficult to access for inclusion in research studies (Heaton, 2004).

Data collection and analysis methods were robust, with most studies using face to face interviews<sup>P2-4,P6,P8,P10</sup> or telephone interviews<sup>P1,P9</sup> to collect data. Four studies<sup>P1,P6,P8,P10</sup> used semi-structured interviews allowing more in-depth data to be collected (Brink e al., 2018). While Thomas et al<sup>P7</sup> held a focus group to gather rich data from the shared discussion (Gerrish & Lathlean, 2015). Owens et al<sup>P5</sup> held an online forum with participants aged 16-25 years, who were familiar with that platform. For the majority of the studies data were analysed by two independent researchers and thematic analysis used to interpret the data<sup>P1,P5-8,P10</sup>. More rigorous reporting of data methods included reaching data saturation and acknowledging researcher reflexivity as seen in three of the studies<sup>P6-8</sup>.

With regards to data reporting, three studies P1,P6,P10 demonstrate clear participant variety in the quotes used, and report raw data which summarised themes well. While two studies P2,P4 provide percentages to demonstrate the frequency of emergent themes rather than reporting richer qualitative data to demonstrate service user experience (Brink et al., 2018). In addition, Fleury et al P2 included quotations as an appendix that could not be accessed, and no response was received from attempts to contact the authors. Consequently, Fleury et al P2 and Harrison et al's P4 studies contributed minimally to the overall synthesis as they provided poor levels of qualitative data. However, the level of rigour improved in the quantitative sections of these papers. Quantitative methods were used alongside qualitative data collection to gather data using surveys and face to face interviews for three studies, with all providing a good rationale for using a mixed method design P2,P4,P9. Service user satisfaction data were collected through face-to-face surveys for two studies P2,P4. Whereas Wand et al P9, contacted participants 72 hours after their ED attendance to conduct telephone interviews.

#### Quantitative results

Three mixed methods papers report results from satisfaction surveys related to service user experience (Table 6). Results from Wise-Harris et al<sup>P10</sup> were not included, as outcome measures did not meet the inclusion criteria. Data reported were heterogeneous in both

nature of the question and measures used<sup>P2,P4,P9</sup>. Harrison et al<sup>P4</sup> report low rates of feeling physically harmed for most participants whereas feeling psychologically harmed or helped was inconclusive. Fleury et al<sup>P2</sup> showed that participants reported mostly positive experiences about staff and the care received. However, Fleury et al<sup>P2</sup> only report the percentage of participants who "agree somewhat or totally", leaving out further data on the other rankings. Lack of follow up care was identified as a concern, and this is consistent with a theme that emerged from the qualitative data<sup>P2,P9</sup>.

# <u>Table 6: Quantitative data on patient experience</u>

# Qualitative themes and synthesis

Five overarching themes were identified from the data, these are illustrated in Figure 2; social constructs, service provider, service provision, effectiveness and emotional impact.

Social constructs, describes the collective ideas that impact on behaviours and beliefs such as stigma and perceptions of inappropriate use of ED. Next is service provider that is centred on the level of understanding and knowledge of staff, their attitude, and skills. Service provision relates to the environment, wait times and the use of restrictive practice as well as structural issues. Effectiveness of the service mainly considers whether participants perceived they had their needs met, and emotional impact relates to service users' emotional experience such as feeling understood or feeling judged. These are discussed in further detail below using illustrative quotes from the data.

#### Figure 2: Themes that influence service user experience

Table 7 outlines the key themes and sub-themes identified. The symbols in each section illustrate when themes were discussed and the context for this. The positive and negative symbols imply whether the theme was discussed as a negative or positive experience. The dot indicates theme discussed in a neutral context. Overall, most studies reported negative experiences except for two studies<sup>P7,P9</sup>.

# Table 7: Themes and sub-themes identified from included studies

#### Theme 1. Social Constructs

#### 1.1 Stigma

Social constructs were identified as key to impacting service user experience in ED. Stigmatising and discriminatory attitudes were perceived by participants in half of the studies<sup>P5-8,P10</sup>. This theme was most prominent in three particular papers; those that explored the experiences of frequent ED users<sup>P8,P10</sup> service user with ID<sup>P6</sup>, and young people who self-harm<sup>P5</sup>:

"Participants described experiencing stigmatizing treatment, with one participant reporting being viewed as "just a psych case" (Wise-Harris et al., 2017:409)<sup>10</sup>.

The nature of the presenting complaint appeared to impact on the amount of prejudice shown. For example, drug and alcohol issues were perceived as being particularly stigmatised:

"I find too that as being an addict, an alcoholic, that sometimes there seems to be... that there's stigma and some prejudices are imposed on me" (Wise-Harris et al., 2017:409)<sup>P10</sup>.

## 1.2. Being "Known"

The idea of *being known* or having repeat attendances also impacted on care received:

"When being known was viewed as a negative influence, the participants explained how ED staff made snap decisions about their reasons for visiting the emergency [department] and spoke to them in an unprofessional way" (Vandyk et al., 2017:6)<sup>P8</sup>.

However, under different circumstances being known impacted positively on care received:

"...seeing a MHLN who was familiar with the individual's situation was identified as helpful, as patients did not have to recount their entire history" (Wand et al., 2016:18)<sup>P9</sup>.

This distinction highlights that it is the service provider's attitude which impacts on the care received rather than the nature of the presenting complaint itself, or factors such as *being known*.

# 1.3. "Appropriate" use of ED

Judgements about the "appropriate use" of the ED strongly influenced service user experience and perceptions of being stigmatised. Participants often justified their attendance as being unavoidable and a last resort:

"The participants described their ED use as necessary and unavoidable in all cases: 'It's when I have nowhere else safe to go. She [community physician] knows and she hates having to send me there, right? You know. Certain times she has no choice.'" (Vandyk et al., 2017:5)<sup>P8</sup>.

Reasons for attending ED included: referral from healthcare professionals in the community, an understanding that this was the appropriate or only option, structural issues such as the lack of alternative and lack of community support. Regardless of participants' views about their inability to avoid attending ED, many participants reported attitudes or responses from staff invalidated their attendance. Some participants explicitly reported being told that their attendance was inappropriate:

"One participant described an exchange with an ED physician highlighting the tension between the patient's belief that the hospital was the right destination and a conflicting organizational viewpoint: '[The Emergency Department doctor] agrees it's like 'yeah I know, we get a lot of patients like this, people think that we do something very magical and ...just fix things and it's just not the way it works here.' ... he just sent me home so quickly."' (Wise-Harris et al., 2017:409)<sup>P10</sup>.

Certain presenting complaints such as psychosis were more accepted than others as valid reasons to attend ED:

"The participants presenting with psychotic symptoms or acute intoxication and withdrawal symptoms felt as though health care providers agreed with their need for emergency care, given their current status. The participants presenting with unmanaged symptoms related to a personality disorder described feeling like health care providers did not believe that they required emergency hospital care" (Vandyk et al., 2018:5)<sup>P8</sup>.

Perceptions of their attendance being "inappropriate" had a negative effect on participant's wellbeing and was viewed as rejection. While structural issues around lack of alternative options and community support caused participants to feel concerned about where they should go in a crisis. Alternatively, where participants were well received, and their attendance validated, this had an immense effect of relief and acceptance:

"There was a sense of comfort in knowing that presenting to ED for mental health support is a genuinely helpful alternative for people in mental distress. 'That experience of going to hospital has changed my whole approach and structure of how I manage my mental illness. Now I know there is this option available and having someone there who understands me and can work through the situation with me'" (Wand et al., 2016:17)<sup>P9</sup>.

#### Theme 2. Service Provider

#### 2.1 Skill

Lack of staff interpersonal skills were most discussed as impacting negatively on service user experience:

"Lack of eye contact during routine requests was identified by over half of the participants as a factor that increased their discomfort and signified a lack of caring: 'If they care, they look at you, they make eye contact, that's how I know they care. In the hospital, they are not giving eye contact to you . . . then you're not getting help

because they are not seeing you.' Abrupt requests delivered with minimal eye contact or without even brief inquiries as to how the patient was feeling were felt by several participants to communicate a negative judgment of them for having mental health issues, or for related actions, such as a suicide attempt. (Harris et al., 2016:16)<sup>P3</sup>.

#### 2.2 Attitude

Staff attitude was discussed in the context of service provider. Specifically, lack of empathy, care and compassion were repeatedly mentioned as approaches that impacted on service user experience. Numerous examples of negative attitudes lacking in compassion were given that left service users feeling unwanted, dismissed, and disrespected:

"These frequent users often described being treated unsympathetically and depicted ED personnel as 'nasty' (01, 25, 87), 'rude' (4, 24, 83), 'smug' and 'sarcastic' (31), 'not always caring' (38) and 'pretty cold like they don't care' (42). One participant described ED nurses as having 'lost that loving feeling' (4) and a number of other participants reported feeling unwelcome" (Wise-Harris et al., 2017:409)<sup>P10</sup>.

Conversely, positive examples of a compassionate approach had a strong positive impact.

"Participants also appreciated company from crisis care staff and individuals designated to stay with them as they awaited care. These individuals ranged from employee staff to police officers and were uniquely influential in providing elements of valued care during participants' care experiences, such as food, supportive communication, and comfort" (Thomas et al., 2018:616)<sup>P7</sup>.

In addition to lack of compassion and care, lack of flexibility and a rigid approach to care was described as harmful and the cause of increasing distress in participants:

"Routine care-related requests can be perceived differently by persons in emotional distress. One participant became greatly distressed with the request to remove her clothes and put on a hospital gown. She suffered from post-traumatic stress disorder (PTSD) and stated, 'For them to be like, 'Hey, just take your clothes off. Change into

this gown.' It's kind of – that triggers me. It's hard for me to go through that.' She did not feel able to articulate her distress related to the request. Another felt that abrupt requests showed a lack of understanding of her emotional vulnerability" (Harris et al., 2016:16)<sup>P3</sup>.

The reverse was also true, that flexibility and a person-centred approach was often appreciated and significantly improved service user experience:

"asking before taking blood 'because the process is triggering for some people'; not requiring them to roll up sleeves when having blood pressure taken 'because she was sensitive to the fact that I probably didn't want to have scars showing'" (Owens et al, 2016:288)<sup>P5</sup>.

#### 2.3. Communication

Communication issues frequently raised included 'sharing information', 'inter-professional communication' and 'supported decision-making'. Sharing information about what to expect, and services available, improved service user experience and mitigated increasing distress, and vice versa:

"Participants valued clarity and timeliness of communication. They described how they appreciated explanation for how the care process would work, whom they would see and when, and details about the admission criteria and treatment options" (Thomas et al., 2018:615)<sup>P7</sup>.

Supported *decision-making* was considered important and when service users were given sufficient information and were consulted on decisions which they were able to impact, they felt respected, and reassured. However, when this was not done service users felt disregarded:

"Others considered that they had been denied information, excluded from decision-making or were talked about as if they were not present" (Owens et al., 2016:288)<sup>5</sup>.

In some cases, participants showed great insight into the complexity of supported decision-making in a time of crisis, yet still valued this where possible:

"Shared decision-making was emphasized as a foundation of quality care.

Participants were well aware that they might not be able, or as able as usual, to participate in shared decision-making during times of crisis. They described valued strategies to address this tension, including transparent communication, treatment planning both before and during crisis care, and attention to their preferences regarding visitors who might or might not aid in decision-making" (Thomas et al., 2018:617)<sup>P7</sup>.

Achieving 'supported decision-making' in a crisis required good 'inter-professional' and 'inter-agency communication' to ensure advance crisis plans were accessible and that professionals were aware of service user preferences. Furthermore, good 'inter-professional communication' gave participants confidence in the system and left them feeling well cared for. Where it was lacking meant that certain decisions might be made in a crisis which were not followed up on in the ongoing plan or it did not fit with pre-existing care plans that the participants were already receiving. Better 'inter-agency communication' was consistently needed to ensure advance care plans were honoured and care was seamless from one service to the next:

"In discussing follow up/discharge plans, most individuals with ID [Intellectual Disabilities] and their caregivers agreed that they were not adequately connected to community services, and crisis plans were not created in partnership with the hospital" (Spassiani et al., 2017:10)<sup>P6</sup>.

# Theme 3. Service provision

#### 3.1. Provision

Wait times were frequently discussed throughout most studies. In studies which had an established MHLN or other emergency psychiatric pathways positive comments included the lack of wait time<sup>P2,P9</sup>. In the remaining studies, negative experiences were exacerbated

by lengthy wait times, minimal communication and limited time being offered when eventually seen:

"First you sit for hours. Even if they put you in the back, you sit for hours. And then you talk to a medical doctor. And then you wait for hours. And they send down a psychiatrist or someone and they talk for a minute or two. Very short." (Vandyk et al., 2017:5)<sup>P8</sup>.

There was often a sense of feeling forgotten which could be mitigated by ongoing communications and acknowledgement of the wait time:

"Generally people expected a long wait and understood this; 'I can understand the waiting time'. However, it appears that during this wait, more could have been done to keep people informed of progress or delays" (Collom et al., 2019:3)<sup>P1</sup>.

#### 3.2 Environment

Concerns reported about the ED environment included the lack of privacy, as well as the noisy, chaotic and clinical nature of the ED. Participants often reported that the environment would play a part in exacerbating already existing symptoms:

"The cold, clinical nature of the ED was noted to increase anxiety for some" (Harris et al., 2016:16)<sup>P3</sup>.

Like the debate around appropriateness of ED for mental health service users, some participants discussed the possibility of a specialist Psychiatric ED:

"Another respondent recommended a separate emergency department entirely for mental health emergencies, stating 'If there was a mental health ED, then we'd go there'" (Collom et al., 2019:3)<sup>P1</sup>.

'Comforts' were also suggested as helpful in improving experiences such as bedding, drinks and snacks.

#### 3.3. Use of restrictive practice

Restrictive practice was perceived as exacerbating symptoms and distress. Specifically, ongoing checks, restraint and perceived lack of choices were identified as contributing factors to negative experiences. Participants reported the fear and/or anticipation of losing their freedom either through being legally detained under the Mental Health Act or simply being excluded from decision-making:

"There is the fear that these will be applied without good cause: 'If you come in saying, 'I hate the world,' one of those comments could wind you up being held against your will if they wanted to'. For one participant, this fear was 'just as scary as the symptoms' for which she was trying to get help. The worry over this possibility results in individuals needing to calculate carefully what they say and do not say, which is difficult because, 'when you are in a crisis it is already hard to control yourself'". (Harris et al., 2016:16-17)<sup>P3</sup>.

Some participants acknowledged the need for restrictive practice and were appreciative of it in retrospect. Here, good communication and supported decision-making was re-iterated as a mitigating factor to the distress experienced with reference to restrictive practice.

#### 3.4. Structural issues

Structural issues such as discharge planning, information sharing, and follow-up care were perceived as ineffective<sup>2</sup> and left participants feeling frustrated and powerless to help themselves:

"They found the process tedious and futile, since it rarely resulted in any treatment or follow-up being offered" (Owens et al., 2016:288)<sup>P5</sup>.

## Theme 4. Effectiveness

#### 4.1. Denied access/treatment

Some participants reported having been denied treatment or access to care:

"Some participants complained of unfair discrimination and of having been denied usual care, including pain relief, on account of having caused their own injuries" (Owens et al., 2016:288)<sup>P5</sup>.

#### 4.2. Needs not being met

Of those that received treatment, few felt the service was effective<sup>4</sup>, with several reporting that they did not feel their needs had been met during their visit to the ED.

#### 4.3. Worsening symptoms

In addition to not having their needs met, participants frequently reported that attending ED exacerbated their condition, due to environmental factors, wait times, discrimination and the attitude to care and this made their symptoms worse:

"Some young people talked about being more likely to self-harm after leaving A&E because of the way it made them feel, and one described feeling like going home and 'finishing the job', i.e. making another, more determined attempt to take her own life" (Owens et al., 2016:288)<sup>P5</sup>.

#### Theme 5. Emotional impact

#### 5.1 Respect

The largely negative emotional impact on the service user is apparent in how participants described feeling unheard or disrespected by lack of communication and supported decision-making. Participants also described feeling 'rushed' either due to the limited amount of time given or due to the attitude of the provider which left the participants feeling unheard:

"The behaviour of ED staff who are under time pressure to efficiently triage and care for patients was interpreted by some participants as indicative of a lack of caring:

'When I see them constantly watching the clock I'm thinking that maybe what I'm really saying to them is not that important...'" (Harris et al., 2016:16)<sup>P3</sup>.

#### 5.2 Validation

Feeling disbelieved or invalidated was often perceived in response to a dismissive attitude:

"The experience of being seen as using the ED inappropriately left some participants feeling ashamed: '...I just started feeling ashamed of going there so much and needing the help...every time I'd think of going ...I like wanted to commit suicide... well they're not going to believe me, they're not going to do anything so, the shame was from their thinking I am lying or an attention seeker, it's pretty disappointing'" (Wise-Harris et al., 2017:409)<sup>P10</sup>.

## 5.3 Rejection

Or feeling that they were an inconvenience:

"P2: [I] took the bus to [the hospital] and stayed there for a while. They didn't really want me there. Interviewer: did you just have the feeling or did they actually use words to tell you they didn't want you there? P2: They told words, yeah." (Spassiani et al., 2017:7)<sup>P6</sup>.

These findings outline how the reported experiences are influenced by service provider attitude and stigma and demonstrate the emotional impact on the service user.

#### Discussion

## **Summary of findings**

This review provides an up-to-date account of the literature addressing experiences of service users attending ED for a mental health crisis. The results show that service user experiences of the ED remains poor and there is a need for service improvement in this area. Five themes were identified that illustrate patient experiences, areas for future

research and need for improvements in integrated care. The evidence builds on Carstensen et al's (2017) review, which found that service users experience high levels of stress and discomfort when attending ED due to staff attitudes, wait times, and the environment. The few positive experiences in our review were mostly reported with reference to specialist services (EPU) or staff (MHLN)<sup>P4,P7</sup>. Such specialist services, however, do not wholly meet the needs of services users who also require emergency physical health care, for example, treatment required following an overdose or a self-harm wound. Thus, further evidencing the need for integrated care.

The five themes identified are: social constructs, service provider, service provision, effectiveness, and the emotional impact on service users. The review identifies social constructs, such as stigma as an overarching factor which impacts on the experiences of service users attending ED for mental health crises. These social constructs impact upon the service providers approach to care and care provision in ED for mental health service users. Service provider and provision in turn, impact upon the service user's emotional responses to and the effectiveness perceived about the service delivered. For example, stigma influences staff attitudes negatively and most prominently influences perceptions of care received. Lack of compassion and flexibility in staff approaches tend to exacerbate service users' symptoms and leave them feeling hopeless. Conversely, showing compassion and empathy significantly improved service user experience. The environment was perceived as being inappropriate and a contributing factor to the increased distress reported by service users. Good communication was identified as a necessity to mitigate negative experiences especially with reference to restrictive practice, but service users rarely felt part of the decision-making process. Structural issues such as lack of options for follow up care and communication between services was emphasised as an area for improvement. Principally, service users report not having their needs met through attending ED and rather their experience contributed to perpetuating their difficulties.

#### Recommendations for clinical practice

Addressing stigma and discrimination towards mental illness should be a priority as it was shown to significantly impact on service user experience. The review shows evidence of interpersonal stigma which impact professional's attitudes and behaviours. Stigma towards [Type here]

mental illness contributes to diagnostic overshadowing and delays the correct treatment with a further risk of complications and mortality (Van Nieuwenhuizen et al., 2013). Stigma can be tackled through education and positive contact with those being stigmatised, these need to be well managed to ensure the learning is meaningful and accurate (NASEM, 2016). Working collaboratively with service users to improve ED services is imperative to reduce stigma. This can be achieved by service users co-delivering training, being involved in quality improvement projects, and working alongside commissioning groups to develop services.

The review describes staff attitudes and lack of understanding, compassion, and flexibility as a key factor which impacts on service user experience. This lack of person centred care is highlighted in other research (Huhtakangas et al., 2020; Quinlivan et al., 2021). Psychosocial assessment in ED can be supportive or harmful dependent on the attitude and approach of the healthcare worker in ED (Quinlivan et al., 2021). Lack of compassion may in part be due to stigma and personal views or reduced self-efficacy and confidence in managing mental health (Clarke et al., 2014; Henderson et al., 2014). Staff training around trauma-informed care can increase understanding and skills in managing mental health which, in turn, improves attitudes (Clarke et al., 2014; Henderson et al., 2014; SAMSHA, 2014). Best practice guidance for liaison mental health recommends teams provide training to relevant ED staff (NHS England, 2016). Ensuring that liaison teams have capacity to provide training is key when commissioning the service.

Lack of compassion has a devastating effect, making service users feel hopeless, rejected and experiencing increased distress and symptoms. Compassion fatigue and burnout in ED staff can result from increased exposure to traumatised individuals and events which can lead to diagnostic overshadowing in mental health service users (Ivanić et al., 2015; Mamede et al, 2017). Compassion can be nurtured through positive role models, reflective practice and experiential learning. Furthermore, leadership approaches demonstrating a tolerance for mistakes are more likely to support staff in developing better attitudes toward service users and reducing stigma (Henderson et al., 2014; Carlström & Ekman, 2012). Whereas emphasis on efficiency and rigid work environments contribute to reduced compassion (Ivanić et al., 2015). There is an inherent tension in the ED environment where efficiency and quick decision-making is required for safe emergency care, but mental health service users require a slowed down and person centred approach for improved

compassionate care. Consideration should be given to achieving a balance between these tensions through leadership and organisational cultures which model both efficiency and person-centred care (Carlström & Ekman, 2012).

Paton et al., (2016) found restrictive practice negatively influences experiences of care. This review found that service users reported feeling afraid of reporting psychological distress and suicidality for fear of being detained. They described feeling coerced and report a lack of information-sharing resulting in some being unaware when they were being detained. Our findings identify a need for improvement around communication and inclusion in decision-making which is reflected in other research specifically around experiences of frequent attenders (Huhtakangas et al., 2020). There was acknowledgement of the complex nature of supported decision-making in a crisis at times when the person may lack capacity to make decisions. Yet, service users appreciated attempts at supported decision-making and involving family, and chosen next of kin, or previously agreed care-plans. Further emphasis on communication and supported decision-making in crisis care will support a move away from the traditionally paternalistic attitude toward the use of restrictive practice (Huhtakangas et al., 2020; Moore et al., 2016).

Overall, the environment in ED was often perceived as inappropriate and a separate space for mental health service users was suggested. In the studies that included specialist EDs, participants spoke about the differences in these environments which were much more calming, reassuring and fit for purpose. UK national guidelines advise that service users who attend ED for self-harm should be offered a safe environment which minimises distress (NICE, 2004). Yet, an appropriate space for psychosocial assessments is often lacking (Jasmin et al., 2019). Creating quiet rooms or making more relaxing spaces available in the ED is needed. Appropriate private spaces allow clinicians to carry out their psychosocial assessments and ensure privacy and the confidentiality of the service user. Offering appropriate environment would help meet service user needs more effectively, as well as legitimise their attendance. Further, providing appropriate spaces for assessment is associated with a sense of legitimacy and identity for the liaison team who may otherwise feel dispirited (Jasmin et al., 2019).

Participants spoke about their experiences in ways that suggested that their visit to ED was ineffective. This is in part, due to the environment and the perceived attitudes of service

providers. Other perceptions focused on structural inadequacies of the system; discharge without treatment or ongoing plan, lack of appropriate community services or alternative resources. Staff in liaison teams report that long wait times and debates over team thresholds and remits can act as barriers when referring for ongoing care (Jasmin et al., 2019). Improved communication and relationships across different teams may improve follow-up as well as more consistent care. Local service evaluations would identify any gaps in provision, and ensure commissioning groups are aware of the areas needing improved resources. Expanding community resources will both contribute to prevention of crises and provide follow-up support in cases of crisis.

Good communication, information sharing and working relationships with primary healthcare providers and other services are recommended as part of the liaison model (NHS England, 2016). Specifically, advance care plans, crisis plans, and service user preferences should be shared across services and be applied to improve person-centred care. There was little mention of shared plans across services and service user often felt frustrated by the lack there-of, for example decisions made to change treatment or medication were not upheld across services. Shared patient record systems are required to improve information sharing and allow professionals to access plans in crisis (Baugh et al., 2020; Jasmin et al., 2019). Jasmin et al., (2019) showed that integrated care systems have improved the communication between local services and increased collaborative working and relationships.

#### Future research

This review highlighted that certain patient groups; those with substance use, frequent attenders to the ED and young people who self-harm, have particularly poor experiences in the ED which is consistent with previous research (Paton et al., 2016). This includes experiences that were harmful and worsened mental health (Paton et al., 2016). Research into iatrogenic harm is required to better understand what contributed to such experiences and what can be mitigated in future. Interventions that focus on more trauma-informed approaches to care delivery in ED may improve staff's understanding about why people self-harm, but research is also needed to establish efficacy in practice (Hall et al., 2016). Evidence-based strategies for managing compassion fatigue and improving diagnostic [Type here]

accuracy are also needed to improve service user outcomes. Evaluating existing training and education-based interventions could identify the best approaches for improving resilience and mental health awareness in ED staff and improve the experiences of service users attending ED in crisis. Trigwell et al., (2015) developed a framework for evaluating clinical outcome and patient satisfaction specifically for liaison mental health. This framework can be used to collate feedback about patient experiences and monitor whether changes being made are effective in meeting the needs of service users.

The review provides a comprehensive overview of the evidence related to service user

# **Limitations**

experience in the ED for mental health crises but has some limitations. Although the screening process, data extraction, and synthesis were largely carried out by one researcher leaving the review process open to bias, at the first stage of screening a second researcher screened 10% of the papers. An inter-rater score was obtained that showed good agreement, thereby adding rigour and validity for the search strategy and screening process. In general, the included papers were of good to moderate quality. Two of the papers included both general EDs and EPUs in their exposure (Fleury et al<sup>P2</sup>; Harrison et al<sup>P4</sup>) however, neither differentiated between these in their results and therefore the validity of the data included from these papers is considered with caution with reference to the aim of the study. These two studies P2,P4 also provided limited qualitative data and attempts to contact the author for unavailable data<sup>P2</sup> were unsuccessful. A sensitivity analysis showed neither of these papers contributed significantly to the overall synthesis of the findings. Only papers written in English were included in the review and the studies were limited to Canada, UK, US and Australia, which leaves the vast majority of countries underrepresented. In particular, the papers were skewed toward a Caucasian population and on some occasions toward females limiting the generalisability of the study to wider populations. Further research should endeavour to be more inclusive and representative of all races and ethnicities. The results may have been skewed by the sample, as patients who have had negative experiences may be more likely to take part in such research studies. Result should be taken into consideration within this context.

The review relates to data published up to 2019. A further search conducted on 21<sup>st</sup> June 2021 found only one new study with papers meeting the search criteria (Wand et al., 2020, 2021). These papers re-evaluate perceptions of the MHLN service<sup>P9</sup> already included in this review and focuses on patient, ED and mental health staff's experiences, so may be of interest to include in future reviews.

#### Conclusion

In conclusion, service user's experiences of attending the ED for a mental health crisis, remain largely negative and further improvements in care provision is needed. To achieve true integrated care, parity of esteem must be evident in the prioritisation of mental health care equally alongside physical care and reducing siloed approaches within healthcare. The findings from this review identify the key areas which should be addressed which are summarised in table 8 below. These are, tackling stigma in mental health and improving person-centred care, providing an appropriate environment for mental health service users in ED and addressing structural issues and gaps in the services to ensure relevant follow up care.

#### Table 8: Key Recommendations based on review findings

## **Relevance to Clinical Practice:**

Our review shows that further improvements are still needed to reduce health inequalities and promote better care for mental health crises in EDs. Service users attending EDs in crisis continue to have negative experiences of care due to stigmatising attitudes and low skill in managing their needs. However, more positive experiences are evident when physical and mental healthcare services are integrated. Mental health liaison teams can help provide support for interventions that address stigma by delivering training to increase mental health awareness, improve staff communication and risk management skills. Additional service developments that address structural issues which promote better interagency working and modify environments will improve mental health service user experience in ED.

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Figure 1: PRISMA Flow Diagram

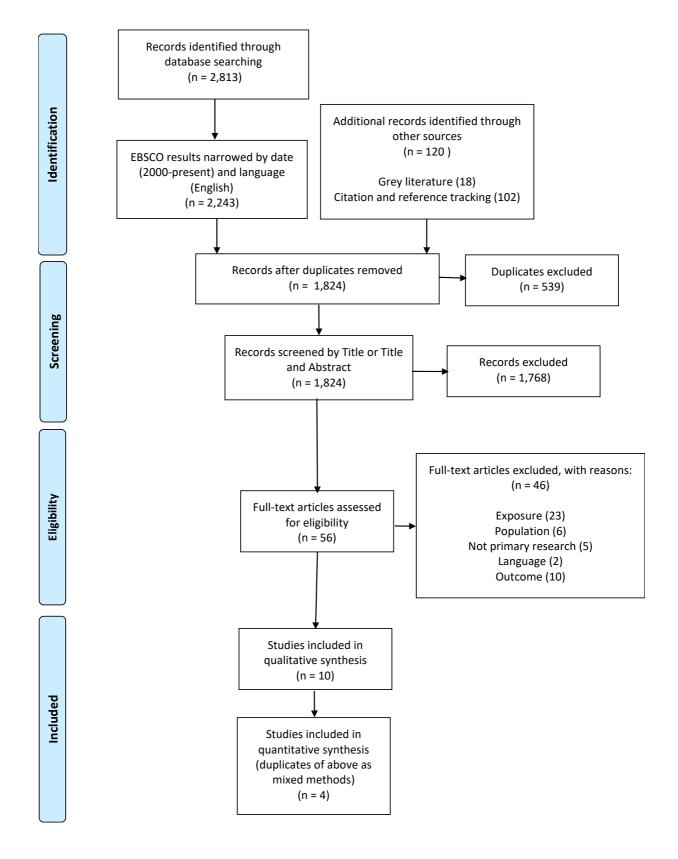


Figure 2: Themes that influence service user experience

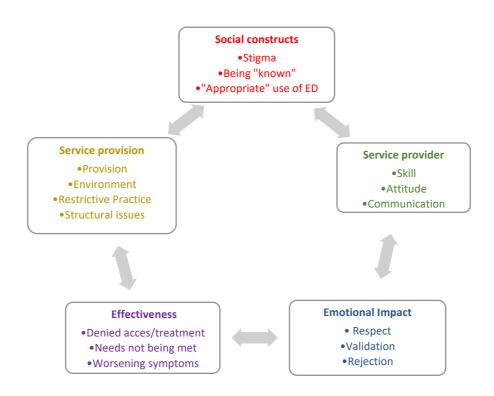


Table 1: Search terms

Exposure	Outcome
"emergency department"	perspective
ED	perception
"emergency room"	opinion
ER	experience
"accident and emergency"	attitude
"ED"	satisf*
RAID	evaluat*
"Psychiatr* N3 liaison"	feedback
	view
	"emergency department"  ED  "emergency room"  ER  "accident and emergency"  "ED"  RAID

Table 2: Eligibility Criteria

	Inclusion	Exclusion
Population	All ages and genders	Service users with mental health histories
	Service users attending ED for a mental health crisis	attending ED for physical health reasons not
	including:	associated with psychiatric illness.
	Suicidal ideation, Self-harm, Psychosis, Drug/alcohol	
	addiction, Anxiety/panic	
Exposure	Accident and emergency departments within a general	All other general hospital settings (acute)
	hospital	Specialist crisis services for mental health
	Including those with specialist provisions available such as	detached from ED (e.g. crisis house)
	psychiatric liaison teams.	Service user satisfaction of other emergency
		care services such as ambulance or police
		Evaluation of a specific intervention or
		screening tool within ED for mental health
		crisis
Outcome	Service User/carer/family experience, perspective, view,	Professional view, experience or perspective
	survey, feedback form, evaluation	
Study characteristics	All study designs	Papers not in the English language
	All countries	Opinion pieces
	2015 – 9th Jan 2020	

Table 3: Study Characteristics of included papers

Ref Authors Year Country	Design	Aim	Context/ Provision in ED	Participants	Participant No Male/Female Age Range Other demographics	Sampling method	Data collection Date and method	Data Analysis	Main findings	Quality of evidence
Collom et al. 2019 <sup>P1</sup> UK	Qualitative	To explore the perceptions and experiences of companions attending the emergency department with loved ones who were presenting for first-time help-seeking with an acute mental health crisis.	One inner- and one outer-London acute general hospital.  24-h liaison psychiatry team with a range of psychiatric, nursing and psychology inputs.	Relatives, friends, companions	9 3M / 6 F 40- 53	Systemic purposive sampling	July-Aug 2015  Semi structured interview Face to face and telephone (1:8)	Thematic Analysis by 2 researchers	Two major themes were identified, the appropriateness of the clinical space and communication with staff including shared decision making and sharing information	Moderate
Fleury et al. 2019 <sup>p2</sup> Canada	Mixed Methods	(1) Evaluate the satisfaction of 328 patients with MH disorders concerning their use of EDs and other MH services	Quebec - 4 EDs with different provisions Specialised Psych ED (ED-P); a psychiatric ED that was a division	ED attendance for MH reasons	328 49% M M = 38.9 (mean age) 80% lived in private homes, post- secondary education	Convenience - Attended EDs at different times of day	Jan-June 2017  Qual: Interview	Coding Univariate	Overall patients were satisfied with staff attituded in ED. Major sources of dissatisfaction were the environment and the lack of follow up from	Qual: Poor
		(hospital in-patient services, outpatient services and community organizations) and (2) Identify specific aspects of EDs and other MH services with which	of a general ED located at a separate site (ED-PG-1); a psychiatric ED merged with a general ED (ED- PG-2); and, a general ED where staff included a number of		(56%), were unemployed (67%) and earned less than \$40,000/year (70%)		Quant: Survey/ Questionnaire	analysis	community services.	Quant: moderate
Harris et al. 2016 <sup>P3</sup> US	Qualitative	patients were most, or least, satisfied. To describe the perceptions of ED visits by persons experiencing emotional distress	additional MH specialists (ED-G) Community based crisis facility (interviewed on previous experiences in ED)	Patients attending crisis treatment centre	9 Majority F 21 - 65	Purposive	2012 (Secondary analysis) Face to face interview audiotaped and	Interpretive process associated with existential phenomenolog y	Three main themes: Environment, attitude and use of restrictive practice. Overarching these themes is clinician approach which can influence the above	Moderate
Harrison et al.	Mixed Methods	To better understand factors relating to the ED experiences of patients with MH	Provision not discussed British Columbia - Large general hospital ED	all MH patients admitted following ED	49 (45% of those initially approached) 51% M 19 – 98 (M = 39.02)	Convenience	transcribed No date Qual: Interview – Likert scale	Not specified	themes.  Reported patient experience was varied with some reporting positive, improved experiences and	Qual: Poor

2015 <sup>P4</sup> Canada		emergencies who are later admitted to psychiatric inpatient units.	EPU - transferred from ED	involuntary/volun tary	White (65%), Aboriginal (10%), Black (8%), Chinese (8%), and a mix of other ethnicities (28%); (8%) endorsed multiple ethnicities		Quant: Survey	Percentage	others reporting an intense chaotic experience.	Quant: Moderate – Poor
Owens et al. 2016 <sup>PS</sup> UK	Qualitative	To examine young people's perceptions of A&E treatment following self-harm and their views on what constitutes a positive clinical encounter.	Online forum in UK  Not discussed	Young people who self-harm	31 97% F 16 – 25 97% white ethnic origin	Purposive	Summer 2009 (Secondary analysis) Online chat Forum	Inductive thematic analysis	Participants report discriminatory and punitive treatment received in ED perpetuating a cycle of shame, avoidance and selfharm.	Strong
Spassiani et al. 2017 <sup>P6</sup> Canada	Qualitative	To describe the stigmatization experienced by adults with ID (Intellectual Disability) living in the community who interacted with emergency services (i.e., police, paramedics, and ED staff) as a result of a psychiatric crisis, from their perspective, and those of their caregivers.	Toronto Not discussed	Patients with Intellectual disability experiencing psychiatric crisis in ED	12 patients, 4 family members, 5 carers 4 M/8 F 16 – 28 75% Caucasian, 3 participants visual minorities, Majority had mild ID, 3 had more severe cognitive impairment	Purposive - community based agencies working with ID and psychiatric crisis	2008-2009  Face to face semi- structures face to face Interview - audio recorded and transcribed	Thematic analysis	Four themes emerged: ID and mental health stigma, stigma preventing people from accessing services, lack of support and concerns regarding care planning. Participants reported feeling dismissed or disrespected by staff and poor transitions between community and hospital care.	Strong
Thomas et al. 2018 <sup>P7</sup> US	Qualitative	To develop a better understanding of what patient with MH and substance related disorders value in order to inform county and state policy on Psychiatric crisis services.	Wake County - North Carolina a comparison of EDs and specialised EPU (WakeBrook) ED vs EPU	All ED attenders with MH	27 52% M 20 – 60 1/3 minority ethnic	Purposive from NAMI, other focus groups and WakeBrook	No date Focus groups (3)	Coding and thematic categorisation	Themes emerged were appreciation for feeling respected, the importance of shred decision making and basic comforts in the environment.	However, reporting of results is not distinct to EPU and ED
Vandyk et al. 2017 <sup>P8</sup> Canada	Qualitative	How do frequent presenters to the ED describe their interactions with health care providers?	Recruited through community mental health service in Ontario Not discussed	Patient who visit ED more than 12 times in a year for MH reasons	10 4 M/ 6 F 22 – 66	Purposive - selected from database, contacted offered opportunity and asked	Spring and summer 2016 Semi-structured face to face interview	Thematic Analysis, inductive, interpretive description (Thorne, 2008)	Participants justified their attendance at ED as necessary and unavoidable. Staff attitudes were perceived as dismissive, disrespectful and prejudiced.	Moderate

about	
interest	

						interest				
Wand et al. 2016 <sup>P9</sup>	Mixed Methods	To evaluate an extended hours nurse practitioner-led mental health liaison nurse (MHLN) service based	Sydney - Royal Prince Alfred Hospital – ED MHLN - Mental Health Liaison Nurse Team	All MH patients seen by MHLN	14 Not specified Not specified	Purposive - Patients who consented in ED were contacted by	Qual: May-July 2013 Telephone interview - recorded and transcribed	Content analysis via open coding.	The MHLN had a positive effect on patient experience. Patients felt understood, reassured and wait times improved.	Qual: Moderate
Australia		in an ED in Sydney Australia.				phone 72hours after visit	Quant: Sep 2012- 2013 Interview - Likert scale	Percentage Mean and SD	Follow up care and transitions to community service require improvement.	Quant: Moderate
Wise- Harris et al. 2017 <sup>P10</sup> Canada	Mixed Methods (Only qual. data included)	To explore perceived need for and experiences of ED utilization of this subpopulation of frequent users in a large urban centre	Toronto - 6 participating hospitals  The Coordinated Access to Care from Hospital Emergency Departments (CATCH-ED)	5 or more visits in past year at least one for MH related reasons	20 of the intervention group 51% M M= 44.5 Canadian born (74 %), Caucasian (67 %), and in receipt of disability benefits (75 %) 10 % of participants had a history of homelessness in the previous 12 months	Purposive	August and December 2013 Face to Face semi- structured interview with open ended questions - Audio recorded and transcribed	Thematic analysis	Participants justified their attendance as necessary. They reported feeling stigmatized with hospital personnel and being discharge without expected treatment.	Moderate

Table 4: Reasons for attendance and number of visits

	Reason for attending												
	Suicidal ideation												
Paper	Multiple	Depression	Self-Harm	or attempt	Anxiety	Drug/alcohol	Psychosis	a year					
Collom et al <sup>P1</sup>	-	-	-	-	-	-	-	-					
Fleury et al <sup>P2</sup>	-	12%	-	28%	11%	30%	-	2.4					
Harris et al <sup>P3</sup>	-	-	-	-	-	-	-	-					
Harrison et al <sup>P4</sup>	63%	41%	-	35%	31%	-	-	-					
Owens et al <sup>P5</sup>	-	-	*	-	-	-	-	-					
Spassiani et al <sup>P6</sup>	-	-	Х	х	-	-	Х	-					
Thomas et al <sup>P7</sup>	-	-	-	-	-	-	-	-					
Vandyk et al <sup>P8</sup>	-	х	х	х	x	х	х	20.4					
Wand et al <sup>P9</sup>	37%	17%	25%	25%	17%	3%	-	-					
Wise-Harris et al <sup>P10</sup>	38%	-	-	-	-	16%	-	12					

<sup>\*</sup>Cutting: 100%; Overdose: 51%, Not eating; 71%, Burning: 45% -: not specified

x : category discussed, no percentage provided

<u>Table 5: MMAT – Quality appraisal</u>

Paper		Collom	Fleury et	Harris	Harrison	Owens	Spassiani	Thomas	Vandyk et	Wand et	Wise-Harris
		et al <sup>P1</sup>	al <sup>P2</sup>	et al <sup>P3</sup>	et al <sup>P4</sup>	et al <sup>P5</sup>	et al <sup>P6</sup>	et al <sup>P7</sup>	al <sup>P8</sup>	al <sup>P9</sup>	et al <sup>P10</sup>
	<b>S1</b>	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Screening	<b>S2</b>	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
	1.1	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Qualitative	1.2	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
	1.3	yes	yes	yes	?	yes	yes	yes	yes	yes	yes
	1.4	yes	?	yes	?	yes	yes	yes	yes	yes	yes
	1.5	yes	?	yes	?	yes	yes	yes	yes	yes	yes
Quantitative	4.1		yes		yes					yes	
descriptive	4.2		yes		yes					?	
	4.3		yes		yes					yes	
	4.4		yes		yes					no	
	4.5		yes		yes					yes	
	5.1		yes		yes					yes	
Mixed	5.2		yes		yes					yes	
Method	5.3		yes		yes					yes	
	5.4		no		no					no	
	5.5.		yes		yes					yes	

<sup>? – &</sup>quot;can't tell"

Table 6: Quantitative data on patient experience

Fleury et al., (2019) <sup>P2</sup>		Harriso	on et al., (	2015) <sup>P4</sup>		Wand et al., (2016) <sup>P9</sup>		
%		5 point Likert	Low	Neutral	High	Mean		
"Agree somewhat or totally"	,	scale	1-2	3	4-5	(Agree) 1 - 4 (Disagree)		
Staff were helpful	95%	Feeling helped	38.7%	18.5%	42.8%	Seen promptly and my	1.85	
						care was streamlined		
Staff had a good opinion of	91%	Psychologically	47%	10.2%	42.8%	I felt listened to and	1.71	
them/treated them fairly		hurt				understood		
They received adequate	78%	Physically	66.7%	6.3%	27%	Included in decision	1.71	
treatment		harmed				making		
They received adequate info	77%	Treated	47.9%	14.6%	37.5%	Interventions and	1.93	
		differently				assessment met needs		
Did not consider information on	40%					Follow up care was	1.86	
community services adequate to						well coordinated		
their needs								
						It was beneficial to a	1.5	
						have specialist MHLN		
						I would recommend	1.14	
						this service for other		
						EDs		
						MHLN was competent	1.14	
						and professional		

Table 7: Themes and sub-themes identified from included studies

"Being	igma g known"										et al <sup>P10</sup>
"Appropria						-	-	-	-		-
	-t-" of FD								-	+	
Skills	"Appropriate" use of ED					-	-	-	-		•
	Knowledge in mental health		+							+	
	Interpersonal, listening skills			-	-		-			+	
	Judgemental/ Understanding			-		+ -	-	-			
Attitude	Kind, helpful				+			+	-		
	Flexible/Inflexible			-		+	-+	+			
	Empathy, compassion		+ -	-		- +	-	+	-		-
Communication	Sharing information					-	-	- •		+	
	Inter-professional						-+	- •			
	Supported decision making	+-			-	-		- •	-		
	Waiting times	-	+ -	-	-				-	+	-
Provision	Staff availability		+-	-							
	Basic needs		+					-+			
	Lack of privacy	-		-				-			
nvironment	Clinical	-		-							
	Chaotic, Noisy	-		-	-						
	Not fit for purpose							-			
	Comfort		+ -					- •			
Use of	Loss of freedom			-				-+•			
restrictive practice	Restraint				-			-			
	Lack of choice			-	-				-		
Structural	Lack of alternative to ED										•
issues	ED as gateway to services										•
	Community services Follow up		+-			-	-+	• -		-	•
Denied acco	ess/treatment					-	-				
Needs (no	t) being met				+	-	-		-	+	-
Worsenin	g symptoms	-		-		-		-	-		
Respect	Rushed, Inconvenience			-			-		-	-	-
	Respect/Disrespect	+	+ -	-			-	-+	- +		-
_	Judged/ Understood			-					-	+	
	Disbelieved/ Reassured			-	-		-	-	-	+	-
_	Cared for/	-				-			+		
	Unwanted,						-		-		-
Rejection Disliked, Rejected Hopelessness,											
	ion -	tion    Understood     Disbelieved/     Reassured     Cared for/     Forgotten     Unwanted,     Disliked, Rejected     Hopelessness,     Worthless	tion  Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness, Worthless	tion  Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness, Worthless	Understood  Disbelieved/ Reassured  Cared for/ Forgotten  Unwanted, Disliked, Rejected  Hopelessness,

<u>Table 8: Key Recommendations based on review findings:</u>

	1.1. Organisational and leadership changes are needed to engender a culture that tackles compassion fatigue
1. Tackling stigma and improving person-	1.2. More training around trauma informed approaches to care would help improve person-centred care
centred care	1.3. Increased collaboration with service users to provide training and contribute to service delivery is important
	for tackling stigma and promoting inclusivity
	1.4. Improving communication and shared decision making specifically when using restrictive practice
2. Creating an environment in ED to meet the	2.1. Provide a comforting and relaxing waiting area
needs of mental health service users	2.2. Provide a confidential space for assessments to take place
	3.1. Local evaluations would identify gaps in service provision and inform priorities for allocation of funding
3. Addressing structural issues in the service	3.2. Better communication to improve continuity of care following ED attendance in a crisis.
	4.1. That is more inclusive of all ethnicities and race to allow for more transferability of results
	4.2. Into specific populations such as young people who self-harm will inform improved practice in these specific
4. Further research	areas of need
4. Fultilet research	4.3. Into iatrogenic harm, trauma informed approaches and training delivery will contribute to the evidence for
	improving practice
	4.4. Continued research in service user experiences in ED to continue to inform the development of services



## PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported				
TITLE							
Title	1	Identify the report as a systematic review.	Title page				
ABSTRACT							
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	1				
INTRODUCTION							
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	4				
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	4-5				
METHODS							
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	5-6 & Table2				
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	5				
Search strategy 7 Present the full search strategies for all databases, registers and websites, including any filters and limits used.							
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.					
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.					
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.					
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	7-8				
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	7				
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A				
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A				
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A				
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	7-8				
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	7				
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A				
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	26				
Reporting bias	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A				



## PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS	•		
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	7 & Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	7 & Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	7-8 & Table 3
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	9-10 & Table 5
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	10-11& Table 6
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	9-10
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	26
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	26
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	9
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	21-22
	23b	Discuss any limitations of the evidence included in the review.	26-27
	23c	Discuss any limitations of the review processes used.	26-27
	23d	Discuss implications of the results for practice, policy, and future research.	22-26
OTHER INFORMA	TION		
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A



## **PRISMA 2020 Checklist**

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <a href="http://www.prisma-statement.org/">http://www.prisma-statement.org/</a>