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Complex mental health difficulties: Learning from the **UNSEEN** study with recommendations for GPs

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Contents

Executive summary

Complex mental health difficulties is a transdiagnostic term used to describe patients with mental ill-health who experience repeated episodes of anxiety and depression, with long-term, frequently unpredictable, changes in mood and difficulties in relationships. These patients often fall between services such as IAPT/Talking Therapies and specialist secondary care mental health teams. The care of patients with complex mental health difficulties represents one of the biggest challenges for general practice and the wider healthcare system.

The UNSEEN study, '**Un**derstanding **se**rvices for people with complex m**en**tal health difficulties', was a two-year research study conducted to examine how general practice can better identify people with complex mental health difficulties and provide high quality care. We carried out interviews with patients and GPs and conducted a database study looking for features in electronic healthcare records which might help us identify patients with complex mental health difficulties. In this document we describe what was learnt from UNSEEN and how this might be helpful for GPs in their day-to-day practice.

Complex mental health difficulties include conditions such as personality disorders, dysthymia and complex PTSD. However, rates of coding in electronic health records or formal diagnosis of these conditions are much lower than the actual prevalence rates and therefore many patients go under-recognised. Following the UNSEEN study, we found seven key areas to think about when considering complex mental health difficulties: (i) early life and antecedents; (ii) emotional regulation difficulties; (iii) social adversity and vulnerabilities; (iv) overlapping mental health-related problems; (iv) comorbid drug and alcohol use or dependence; (v) patterns of prescribing; and (vii) service use patterns.

In interviews, GPs recognised this group of patients and highlighted the significant workload and management challenges. GPs expressed frustrations with services and being left holding patients but also described positive experiences of working with newer primary care transformation teams. Continuity of care, allowing time and space for patients, and promoting an empathic culture within the wider practice team were all considered important. Patients with lived experience of complex mental health difficulties described their experiences of trauma and adverse childhood experiences being central to how they made sense of their diagnoses. Their experiences of trying to obtain help from their GP mirrored what we heard in clinician interviews.

The challenges experienced on both sides often result in GPs and patients being left frustrated with unsatisfactory consultations and a perception of little progress despite significant efforts. It can be easy to overlook the importance of good general practice in such situations. However, patients in UNSEEN expressed a great deal of positivity towards their relationships with their GPs despite the difficulties experienced.

Bringing together what we have learned from UNSEEN, we have provided some suggestions to be used in consultations. Ultimately, every patient will be different and have their own story and challenges, but we hope that this document will raise awareness and provide a few practical tips in managing complex mental health difficulties.

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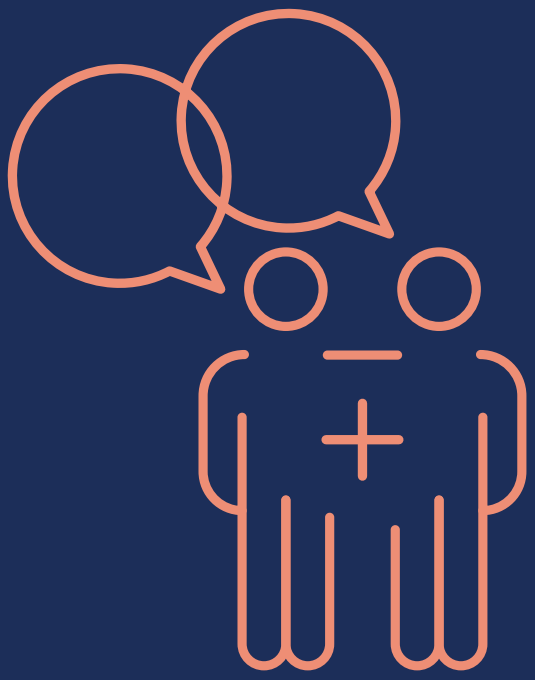

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The UNSEEN study is based [in part] on data from Connected Bradford (REC 18/YH/0200 & 22/EM/0127). The data is provided by the citizens of Bradford and district, and collected by the NHS, DfE and other organisations as part of their care and support. The interpretation and conclusions contained in this study are those of the authors alone. The NHS, DfE and other organisations do not accept responsibility for inferences and conclusions derived from their data by third parties.

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Introduction and background

Mental health represents one of the biggest healthcare problems faced by society. Mental ill-health results in distress for the individual which can ripple through families and communities. It is one of the leading causes of morbidity and mortality among young people and is the leading cause of disability in the UK.

The estimated cost to the economy is in the region of £100 billion per year - more than half of the annual NHS budget. Healthcare services in the UK and other countries are experiencing unprecedented challenges as a consequence of staff and funding shortages, health inequalities, ageing populations, and the increasing clinical complexity of patients. This complexity extends to both physical and mental health conditions.

£100 billion

More than half of the annual NHS budget spent on mental health issues

Mental health service provision in the UK has historically been distributed mainly towards contrasting ends of the spectrum of severity of illness, with the NHS Talking Therapies/IAPT service catering for those with mild to moderate difficulties and secondary care services managing conditions such as psychosis and bipolar disorder. However, significant numbers of patients find themselves being told that they are too complex for IAPT services yet do not reach the threshold for specialist services. General practitioners (GPs) are then faced with the challenge of how best to manage such patients. Inevitably, many patients lose faith in services and fall through the cracks, resulting in patterns of episodic, crisis-driven care.

The NHS Community Mental Health Framework for Adults and Older Adults published in September 2019 provided a blueprint for services to be developed at a community level, including mental health practitioners based within primary care networks (PCNs). Several UK sites went on to pilot the Primary and Community Mental Health Transformation Programme with the aim of catering better for people with mental ill-health with more complex needs by placing multidisciplinary mental health staff within PCNs. Although not all areas have access to such services, networks are now able to employ adult mental health practitioners through the Additional Roles Reimbursement Scheme (ARRS) to "support adults and older adults with complex mental health needs whose main need is not anxiety or depression."

What are complex mental health difficulties?

We use the term complex mental health difficulties to refer to the experience of repeated episodes of anxiety and depression, with long-term, frequently unpredictable, changes in mood and difficulties in relationships. This is distinct from **severe mental illness** (e.g., schizophrenia or bipolar disorder) and **common mental disorders** such as anxiety and depression. This term includes diagnoses such as personality disorders, persistent depression (dysthymia), comorbid substance misuse, neuro-developmental issues and the consequences of trauma. We use **complex mental health difficulties** as a transdiagnostic term which recognises that these diagnoses are hard to access, changing, and potentially stigmatising. People with complex mental health disorders frequently fall between specialist mental health services and community-based services such as NHS Talking Therapies (formerly IAPT).

Because of the unique challenges associated with providing care for people with complex mental health difficulties, many GPs will instantly recognise some such patients among their personal lists. Patients themselves also often self-identify as having mental health difficulties that are "more than just depression or anxiety". However, there is a large amount of evidence that this group of patients is under-recognised more widely. This was the motivation for our NIHR-funded **Understanding Services** for people with **Complex Mental Health Difficulties** (UNSEEN) mixed-methods study which forms the basis of the contents of this guide.

Why does this matter?

People with complex mental health difficulties, particularly personality disorders, have poor physical and mental health outcomes. They are high users of primary care, emergency and crisis services and have increased rates of self-harm and suicidal behaviours. Recognising that a patient has complex mental health difficulties is an essential step in providing appropriate care and support for the patient and their families, especially as there is evidence that people with complex mental health difficulties respond less well to established treatments for common mental health problems.

Coded diagnoses of conditions associated with complex mental health difficulties can be helpful but may not be a reliable absence indicator as rates of diagnostic coding in primary care electronic health records (EHRs) for these are low. For example, the prevalence of personality disorders is estimated to be around 5% in the general population and around 25% in primary care patients with mental health difficulties. We found that less than one percent of patients have a diagnostic code for personality disorder within their EHR. This under-coding may be due to several factors (beyond known general issues with the accuracy of clinical coding), including social pressures and biases that discourage making diagnoses such as personality disorder and/or a reluctance on the part of the clinician to add a code due to uncertainty or perceived inexperience. It may also reflect under-recognition by practitioners working to guidelines for common mental disorders such as depression and anxiety.

Understanding services for people with complex mental health difficulties: UNSEEN

UNSEEN was a 2-year research study, conducted in the North of England, which aimed to examine how general practice can better identify people with complex mental health difficulties and provide care that integrates primary care and specialist psychological input. We used a mixed methods approach, combining interview data obtained from patients and GPs to gain perspectives on complex mental health difficulties and conducted a large database study using the Connected Bradford database to try to identify useful features in patients' EHRs. People with lived experience of mental ill-health were involved in UNSEEN as research participants. In addition to this, an expert by experience panel was also set up to guide each stage of the research process (see Box 1).

BOX 1: How people with lived experience were involved in UNSEEN	
Recruitment of research staff	Involved in the recruitment process for the employment of the research staff involved in the study.
Study Design and Development	Reviewed and piloted the topic guide. Suggested feedback for interviewer and interview process. Supported the development of patient facing materials.
Data analysis	Participated in the collaborative coding of interview transcripts and development of themes.
Dissemination	Identified key audiences for involvement in the stakeholder meetings. Co-production of research articles and dissemination activities.

Aims of this guide

The aim of this guide is to summarise what we learnt from the UNSEEN research and how this may be used to improve patient care . We will describe the challenges in identifying complex mental health difficulties from electronic health records and how they might be recognised in day-to-day patient encounters. The patient voice is crucial to this narrative as are the experiences of GPs who are faced with the challenge of managing this complexity within an embattled health care system. Finally, we will provide some general tips which have come out of this work, along with some resources which we hope you will find useful.

Recognition

Several mental health-related diagnoses are associated with complex mental health difficulties including personality disorders, dysthymia and complex PTSD. We know, however, that these conditions are under-recognised and infrequently coded in electronic health records. We found seven key features associated with complex mental health difficulties:

1. Early life and antecedents

Many patients with complex mental health difficulties have experienced trauma and adverse childhood experiences. They may not describe them straight away, may have normalised them, and they may not be coded in the record.

Action: Look for references to child safeguarding in the past.

2. Emotional regulation difficulties

Difficulties with emotional regulation are extremely common. This may be experienced as mood swings and lead to significant impacts on relationships. Episodic crisis-driven care is a common feature.

Action: Ask how mood changes affect relationships (and vice versa).

3. Social adversity and vulnerability

Patients with complex mental health difficulties may be experiencing multiple social vulnerabilities such as poverty, housing difficulties, and homelessness as well as complex family adversities.

Action: Ask "are you safe" and "who is there for you"?

4. Overlapping mental health-related problems

Patients with complex mental health difficulties may experience symptoms which cut across a spectrum of mental health disorders including low mood, severe anxiety, emotional lability, self-harm and suicidal behaviours. The presence of co-morbid neurodiversity is often seen or suspected.

Action: Look for codes for multiple mental health diagnoses (anxiety, depression, PTSD, panic disorder, obsessive compulsive disorder).

5. Comorbid drug and alcohol misuse/ dependence

Drug and alcohol use are often features of complex mental health difficulties and can pose particular challenges.

Action: Ask about use and or dependence. Recognise that dual diagnosis is common.

6. Patterns of prescribing

Several patterns of prescribing might indicate complex mental health difficulties. These include multiple antidepressant switches with little evidence of benefit and prescribing of antipsychotic medication without a clear indication.

Action: Check how many different antidepressants have been tried, and whether antidepressants have been started then abandoned? Look for the presence of past or present anti-psychotic prescriptions.

7. Referral and service use patterns

Features of patients with complex mental health difficulties include rejection of referrals by services; patterns of high use of out-of-hours, crisis or emergency services; and challenges around engagement.

Lessons from taking a big data approach

In UNSEEN, we looked at an extensive range of features based upon those described above within patients' Electronic Health Records (EHRs) to see if any might allow us to identify complex mental health difficulties systematically (Box 2).

Several features such as number of mental health diagnoses, prescription for antipsychotic drugs (with no code for severe mental illness) and unpredictability of attendance or non-attendance were weakly associated with the presence of diagnostic codes. On the one hand, this provides support for many of the ideas that came out of our interview studies. On the other hand, the signals in GP electronic records are not currently strong enough to produce an exact risk score. This means that the features we found are useful as pointers to further questions and thoughts, but don't in any way replace a personal assessment of each individual.

Box 2: UNSEEN electronic healthcare record study

In UNSEEN, we attempted to find features within patients' primary-care electronic healthcare records that were associated with a diagnostic code indicative of complex mental health difficulties (such as personality disorder). We used an information-theoretic approach applied to data from the Connected Bradford database to evaluate over 500,000 features including individual codes, groups of codes and patterns of codes or prescriptions in the data. The study was limited because most people with complex mental health difficulties currently don't have a diagnostic code (e.g. for personality disorder) although many would meet the criteria if tested.

GP and patient perspectives

In UNSEEN, we conducted interviews with 11 GPs from the South Yorkshire and Bassetlaw area from a range of locations which included practices located in areas with high levels of deprivation. Nineteen patients from these practices who had coded diagnoses associated with complex mental health difficulties such as personality disorder were also interviewed. These interviews were analysed using a rigorous qualitative method called reflective thematic analysis in order to generate important insights (see Box 3).

BOX 3: What is Thematic Analysis

Reflective thematic analysis is a qualitative research method that involves systematically identifying, analysing, and interpreting themes within reflective data. It is commonly used in the exploration of personal experiences, thoughts, and emotions. The process begins with familiarisation with the data, followed by generating initial codes and searching for patterns or themes. Reflective thematic analysis emphasises the researcher's engagement with the data, encouraging a reflexive and iterative approach. This method is particularly well-suited for exploring complex and subjective phenomena, allowing for a nuanced understanding of participants' perspectives. By organising data into themes, researchers can uncover underlying meanings, contributing to a deeper understanding of individual experiences.

GP perspectives

It is well established that a significant proportion of GP consultations are mental health related. The perception of GPs involved in the UNSEEN interviews was that complex mental health difficulties accounted for a great deal of these and a considerable amount of their overall workload (Quote 1). General practitioners recognised people with complex mental health difficulties as those who do not fit comfortably into the established models of mental health service provision but who might be otherwise difficult to define. Although the term "complex mental health difficulties" was far from perfect, there was consensus on the importance of having a common language for engaging with patients. General practitioners told us that this group could be recognised by those being "bounced around" the system but also by the presence of multiple social determinants of poorer mental health such as a history of trauma, current relationship difficulties, domestic violence, poverty, and comorbid drug or alcohol misuse.

Quote 1:

> …50% of our consultations are to do with mental health problems. And in our practice, a lot of those are complex mental health problems. We're dealing day in and day out with people with complex mental health problems, and I think even if we had all the resources in the world, we'd still be dealing with them, and they would still be making our consultations very difficult because often they present with physical things that are actually due to their mental health problems.

General practitioners reflected that there appeared to be unrealistic expectations of their role in managing people with complex mental health difficulties who require more specialist support. As a consequence of patients being rejected by services, GPs were often in a position of several 'holding relationships' (Box 4). Such relationships can be rewarding (and valued by patients), but also challenging and stressful, as patients are often at higher risk of suicide or self-harm and may be experiencing a myriad difficult interpersonal or social difficulties. Typically, consultations overrun and there can be a perception of little progress or patient benefit.

Box 4: What is Holding?

Cocksedge and colleagues (2011) define holding as a 'doctor-patient relationship establishing and maintaining a trusting, constant, reliable relationship that is concerned with ongoing support without expectation of cure'

The emergence of Primary Care Mental Health Teams (PCMHTs) within GP networks was universally welcomed for this group of patients. However, there were descriptions of these services themselves becoming quickly overwhelmed, reflecting the degree of unmet need and validating GP's own experience of the workload burden associated with managing complex mental health difficulties. Community Mental Health Teams (CMHTs) - themselves facing extreme challenges in managing demand - have long waiting lists and increasingly high clinical thresholds. The result of this is often the rejection of GP referrals, which can erode patient and GP trust in the system, add to patients' mental health burden and damage the relationship between the GP and patient. General practitioners working with diverse populations also reported a lack of culturally appropriate services for people with complex mental health difficulties.

We know that for some patients the process of obtaining an appointment and attending a consultation can be a daunting experience. Upskilling wider practice staff about complex mental difficulties was felt to be important due to a greater risk of misunderstanding in social interactions, difficulty in understanding intentions, or problems with emotional regulation within these contexts. Promoting a non-judgemental and empathic culture for the primary care team was felt to help. In clinical interactions, the importance of continuity of care and taking time to listen was highlighted by GPs who had been asked what they have found helpful in managing complex mental health difficulties (Quote 2).

Quote 2

> So, to get that bigger picture takes time with an individual, it takes curiosity, and it takes a willingness to slow down and to listen…

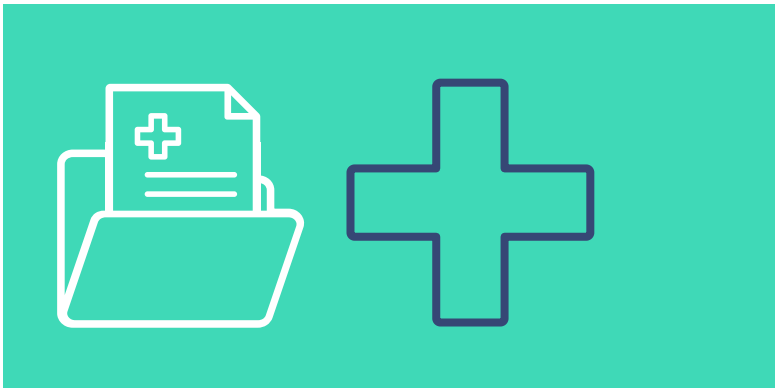
Whilst antidepressants will have an important role for many, the effectiveness for this group was questioned and patterns of multiple switches without apparent benefit were recognised. GPs admitted candidly that this was, in some cases, due to an internal pressure to feel that something was being tried to help in the face of limited alternatives. The most positive experiences GPs reported were in the context of multi-disciplinary collaborative working both with mental health workers attached to practices or networks. The benefits of social prescribing were also highlighted.

Patients' experiences

Patients told us about their lived experience and how they made sense of their mental health difficulties. Central to this was the experience of trauma and adverse childhood experiences. Patients self-identified with the term complex mental health difficulties and talked about the impact of receiving a specific diagnosis (such as personality disorder) in both a positive and negative light. Whereas a diagnosis was described as strengthening a sense of self and providing a focus for treatments, there were concerns raised by some around how diagnoses were communicated. During periods of crisis, patients sometimes resorted to maladaptive coping mechanisms such as drinking and drug-taking as well as self-harm. However, we also heard about more positive coping methods such as journaling or engaging in creative outlets (Quote 3) .

Quote 3

> I get a journal, and I write down everything if I'm in a dark place or, well, I write down everything every day; it doesn't have to be – it could be depressing, or it could be really belly laughing sort of stuff…



A common theme from interviews was how patients experience seeking help from their GP. The challenges described by GPs around referral to specialist services were also experienced by patients. There was a sense of being "passed around", referred into a "void" or simply not being taken seriously. Some of the frustrations that patients experienced were interpreted as GPs displaying a lack of mental health awareness, however, patients with complex mental health difficulties also talked about things that they valued from their GPs. This included continuity of care and regular appointments which were seen as "safety nets" (Quote 4). Patients also highlighted the importance of validation of difficult experiences and of being heard.

Quote 4

> …[My GP] was really good, and since September, she always makes me an appointment, like, every three weeks or every month to check on me and even if it was like for […] to check everything was alright, I think that was pretty good because it made me feel a bit more secure

Secondary care services were viewed as being inaccessible with long waiting lists making patients feel that they were essentially "lost in the system". Patients raised concerns in particular around the response of services at times of crisis, describing difficulties in accessing help, lack of coordinated care, being left alone, a sense of rejection and a lack of follow-up care.

What can you do?

Bringing together the findings from UNSEEN we have put together the following suggestions to help in working with patients with complex mental health difficulties:

Listen, validate, explain and support

It is important to take time to listen and validate experiences. Many patients will not have received a diagnosis beyond "simple" depression or anxiety. Explain that you recognise that their mental health difficulties and experiences extend beyond this.

Consultations

It is clear that consultations with people with complex mental health difficulties take time. Plan for this where possible, for example by considering double appointments and flagging this on patients records so that admin staff are aware. Some people prefer face-to-face appointments, but others prefer the separation that a phone call allows.

Continuity of care

Whilst not always possible, continuity of care is highly valued by patients with complex mental health difficulties. Continuity helps patients build trust and learn that they have been heard. This is important because many people with CMHD find it difficult to know that they have been heard and to trust others (including health professionals).

Provide practical support for life situations

Crises or a deterioration in mental health are frequent reasons for consultations and are often precipitated by social difficulties. Acknowledge these with empathy. Knowing how to access available practical support services and the local range of social prescribing options is useful. However signposting alone may not address the emotional needs which are present in a crisis.

Foster adaptive coping strategies

Adaptive coping strategies will differ from person-to-person but may include things like relaxation techniques, exercise or writing down thoughts and feelings.

Set expectations when referring

It is important to have frank and open discussions when referring, especially in situations where long waiting times are expected or at the margins of referral thresholds.

Protecting yourself

Patients with complex mental health difficulties may be in distress, express suicidal thoughts and describe trauma explicitly. The psychological burden of this can be significant. Consultations may be overwhelming on both sides. It is important to find ways in which your practice can come together to discuss and debrief in a supportive environment and try to ensure that your workload burden is not too heavily weighted towards complex mental health.

Resources & further reading

General reading and resources
Working effectively to support people with personality disorder in the community guidebook: **https://www.candi.nhs.uk/sites/default/files/Documents/practitionerguide_0.pdf**

NICE guideline for Self-Harm: assessment, management and preventing recurrence: https://www.nice.org.uk/guidance/ng225/resources/selfharm-assessment-management-and-preventing-recurrence-pdf-66143837346757

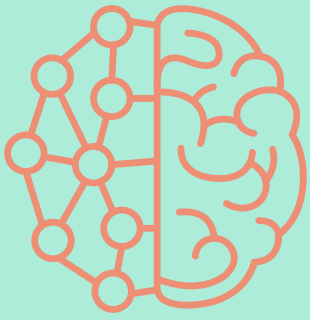
Dixon-Gordon KL, Whalen DJ, Layden BK, Chapman AL. **A Systematic Review of Personality Disorders and Health Outcomes**. Can Psychol. 2015 May;56(2):168-190. doi: 10.1037/cap0000024. Epub 2015 Oct 15. PMID: 26456998; PMCID: PMC4597592.

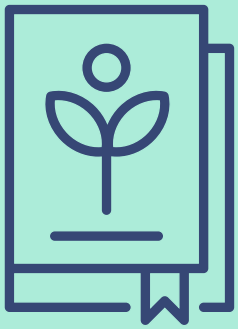
Cocksedge S, Greenfield R, Nugent GK, Chew-Graham C. Holding relationships in primary care: a qualitative exploration of doctors' and patients' perceptions. Br J Gen Pract. 2011 Aug;61(589):e484-91. doi: 10.3399/bjgp11X588457. PMID: 21801542; PMCID: PMC3145532.

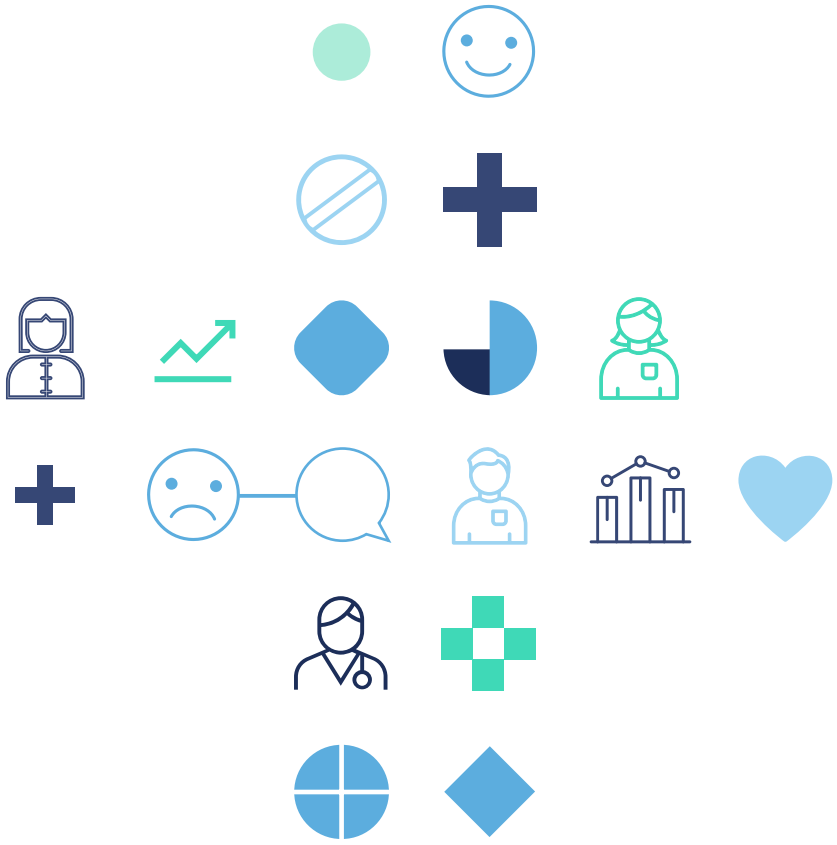
Evaluation of the Sheffield Primary and Community Mental Health Transformation Programme: https://www.sheffield.ac.uk/sites/default/files/2022-09/Sheffield%20PCMHTP%20Evaluation%20Report_FINAL.pdf

Practitioner wellbeing
NHS Practitioner Health Service: Practitioner Health is a free, confidential NHS primary care mental health and addiction service with expertise in treating health & care professionals: **https://www.practitionerhealth.nhs.uk**

Frontline19 is a free independent, confidential and UK based nationwide service delivering psychological support to people working on the frontline: **https://www.frontline19.com**







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