



The lived experience of self-care in mental health in Essex



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healthwatch
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We are indebted to the service users who participated in this study by sharing their views on self-care and experiences of interacting with primary care mental health services and professionals in Essex. These narratives offer rare and invaluable insights into how improvements might be made and we hope that future service users will benefit from this work.

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LIST OF ABBREVIATIONS

CCG: Clinical Commissioning Group

CMHPs: Common Mental Health Problems

GP: General Practices/General Practitioners

HWE: Healthwatch Essex

IAPT: Improving Access to Psychological Services

NHS: National Health Service

NICE: National Institute for Health and Clinical Excellence

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1.0

Executive summary

BACKGROUND

The concept of self-care has sparked a lot of interest over the last few years; service users, health professionals, the media, and politicians employ the concept in discussions about the extent to which people should be responsible for looking after their own health. Whilst much research has been devoted to how people with long term conditions (e.g. diabetes) practice self-care, the ways that people with mental health conditions, such as anxiety and/or depression, think about and practice self-care have scarcely been considered. Within this context, Healthwatch Essex's research team explored how people in Essex understand self-care in mental health and how primary care services support them in practicing self-care.

METHODS

Three group discussions were held in different locations in Essex during January 2017 with a total of 12 participants; Chelmsford (5 participants), Harlow (3 participants) and Rayleigh (4 participants). We employed the method of deliberation-orientated focus groups to gain an in-depth understanding of people's views on self-care in mental health and how primary care mental health services support them in practicing self-care. The average age of participants was 54 years. All participants had received, either in the past or recently, a diagnosis of anxiety and/or depression. The majority of participants (8 out of 12) had been prescribed medication; a small proportion reported that they were also receiving private counselling.

FINDINGS

The findings show that views of self-care and the activities that constitute self-care in mental health are not static; they change and readjust depending on the evolving condition of the person and changes in functioning. Contextual factors (e.g. social and physical health problems) were reported to influence participants' ability and motivation to practice self-care. Receiving professional support was an integral part of participants' self-care routine during periods of distress and recovery. Participants reported that, in their current form, primary care mental health services do not support them in practicing self-care; difficulties with access and continuity of care as well as problematic interactions with GPs contributed to the limited support they received. Our findings show that consistent support from trained healthcare professionals coupled with timely, easy access to services that provide choice and respect patients' pace of recovery enable them to practice more effective self-care.

RECOMMENDATIONS FOR GPs INTERACTING WITH PEOPLE EXPERIENCING ANXIETY AND/OR DEPRESSION

- 1.** Do not just look for symptoms; look also for stories and explore how these stories contribute either positively or negatively to peoples' emotions, thinking, social situation, and identity. Explore how your patients understand self-care and which activities they believe can contribute towards improving and/or maintaining positive mental health.
- 2.** You are already part of your patients' self-care routine if, during your encounters, you use your everyday human skills of empathy, active listening, and a non-judgemental stance towards them. It is important to make them feel that their mental health concerns are listened to and acknowledged. Such practices can make your patient feel valued, which can motivate them to practice self-care.
- 3.** Avoid making any assumptions; instead show an interest and ask your patient how they view their problems or the reasons they believe they experience emotional distress. Be patient and give them time to express themselves. Use open-ended questions and expressions that will permit your patient to talk about themselves. This will allow rapport and trust to develop between you. Make sure that your patient is comfortable discussing these issues.
- 4.** Work with the patient and not on the patient; create partnerships and share decision-making. Your patient is very likely to welcome your support and advice on how to practice self-care. Explore what is important for them and what they need. Identify issues that may affect their ability to practice self-care, such as social and physical health problems. Provide consistent support by scheduling regular follow-up meetings, even during times when the patient is (or appears to be) doing well, to provide reassurance and support.
- 5.** Get familiar with the mental health care services offered in your locality; establish systems that will enable you to get updates about the range and availability of such services.

RECOMMENDATIONS FOR SERVICE PROVIDERS AND COMMISSIONERS

- 1.** Service users consider seeking and receiving professional support to be an integral aspect of practicing self-care. Create simple and easy to understand pathways for people to access mental health services. Set up and/or promote awareness campaigns about the mental health services that you deliver in your locality and provide clear and concise information about how people can access them.
- 2.** All healthcare staff across the healthcare system (e.g. primary and secondary care) who are likely to interact with people who experience mental health difficulties should receive mandatory training in mental health. Such training would aim at improving staffs' communication skills and ability to respond with compassion when they interact with an individual who experiences emotional distress.
- 3.** Focus on prevention by developing educational programmes that will help people to learn how to acknowledge and accept their emotions; design and offer activities that can assist people with practicing self-care in mental health.
- 4.** Offer to service users the opportunity to choose their own care; personalised mental health care budgets might present an opportunity for service users to decide what treatment modality or activity can better address their mental health needs (e.g. going to the gym, attending yoga classes).
- 5.** Consider developing a service equipped with trained staff capable of providing mental health care and support 24/7. Such service will support people who cannot access a GP (e.g. during weekends/evenings), and are not suicidal or at risk so would not be likely to contact Samaritans or be accepted by Accident and Emergency services.
- 6.** Support and encourage the development of peer support groups in your locality (or GP practice); such groups allow patients to interact with people experiencing similar mental health problems, share their experiences and help each other. Consider the possibility of employing experts by experience to train GPs in providing mental healthcare.
- 7.** Individual recovery should determine the length of therapy as opposed to pre-determined time-limited therapy; many participants felt that the support they had received was insufficient to address their mental health needs.
- 8.** Aim to provide a wider choice of evidence-based psychological interventions to patients; patients should receive high quality information about the range of evidence-based therapies available. If service users' preferred therapy is not offered locally, provide information about where the preferred therapy is provided and how they can access it.
- 9.** Set up explicit targets from referral to assessment to treatment; ensure that patients receive treatment within 28 days of referral and assessment (as per national guidance).

2.0

The research study



This report presents a research study that is focused on service users' experiences; the study examined how people who experience low mood and/or stress take care of their mental health, and how primary care mental health services (e.g. General Practitioners, Improving Access to Psychological Therapy Services) support them in that. Throughout this report we employ the concept of 'self-care'¹ to capture the range of actions that people think of and take in order to take care of their own mental health and lives.

The concept of self-care has sparked a lot of interest over the last few years; service users, health professionals, the media, and politicians employ the concept in discussions about the extent to which people should be responsible for looking after their own health. Whilst much research has been devoted to how people with long-term conditions (e.g. diabetes) practice self-care, the ways that people with mental health conditions, such as anxiety and/or depression, think about and practice self-care have scarcely been considered. Within this context, Healthwatch Essex's research team explored how the people in Essex understand self-care in mental health and how primary care services support them in practicing self-care.

Examining peoples' views on self-care and identifying their self-care behaviours can provide valuable insights to health policy makers and clinical commissioners to develop responsive and supportive primary care mental health services. The focus of the current study was on primary care mental health services, as these are the main providers of care for people who experience mild to moderate mental health problems (such as anxiety and/or depression). In this study, we used the focus group method (or group discussion) to collect peoples' views and experiences of self-care and interactions with healthcare professionals and services, as it allowed for the exploration of personal meanings and the capturing of multiple realities that may exist for people.

The study, which was conducted between September 2016 and January 2017, was carried out in the regions of West Essex (Harlow), Mid Essex (Chelmsford), and South East Essex (Rayleigh). One focus group was held in each of these three locations.

¹ We elaborate on this concept in Section 3.1

3.0

Healthwatch Essex: Who we are and what we do

This research project has been conducted by Healthwatch Essex (HWE), an independent charity with responsibilities under the Health and Social Care Act (2012)¹ to provide a voice to the people of Essex regarding health and social care services. The research team conducts high quality academic research on the “lived experience” of patients, social care users, and citizens, to inform improvements in local health and social care commissioning and provision.

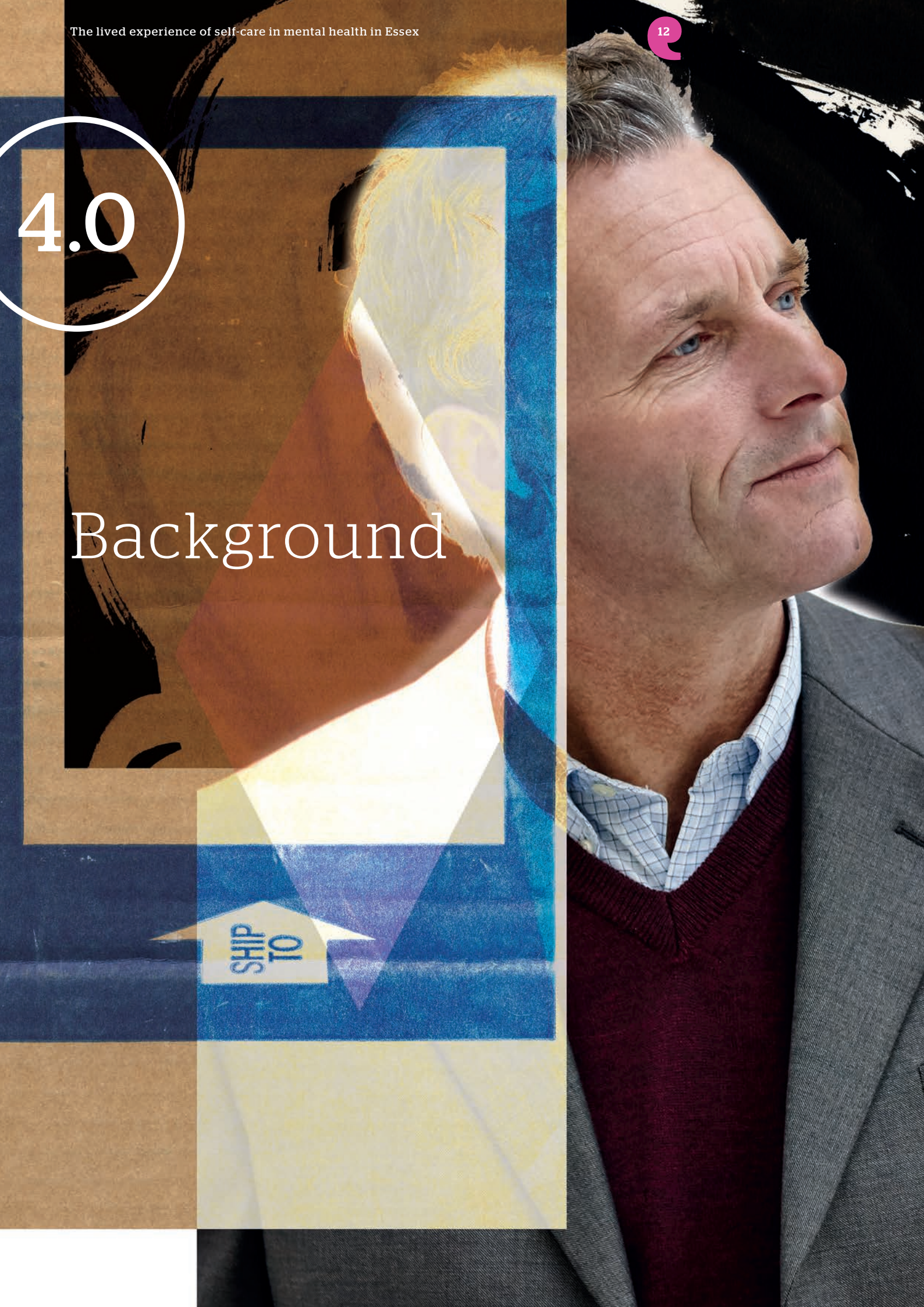
Health policy makers and clinical commissioners plan and fund services using information from a range of sources, such as clinical knowledge (e.g. what health professionals know about diseases), experimental evidence (e.g. what is the best medicine for a particular disease), and public and patient feedback and choice (e.g. how people experience an illness and the care they receive from services). The role of Healthwatch Essex is to assist both local government and clinical commissioners to develop and improve services (including

primary and secondary health services as well as social care services) by investigating how the people in Essex understand illness, how they interpret their experiences, and whether the care they receive meets their needs. To gain an insight in peoples’ experiences of health, illness and care, we use a range of methods: for example, we distribute questionnaires, we carry out individual interviews, and/or organise discussions with groups of people (e.g. focus groups). However, care is not delivered in a vacuum; healthcare professionals and the wider system of care (e.g. emergency and community hospitals, health policy) play a vital role in how care is planned and delivered, and therefore, they influence how patients and service users experience care. Hence, our focus is also placed on services; we explore what professionals think about the care they deliver, which and how different factors affect care quality, and how health and social care professionals believe that services could be improved to meet service users’ care needs².

²Although in this study we focus only on service users’ experiences and views.

4.0

Background



4.1. WHAT IS SELF-CARE?

The concept of self-care has received much attention in recent years as part of a patient-centred approach in the management of long-term conditions and in maintaining good health by living a healthy lifestyle². The concept of self-care became widely known during the 1970s and is associated with 'a desire to enable and allow people to take the initiative in being responsible for their own health care when it is possible'³. In 1983, the World Health Organisation defined self-care as 'the activities individuals, families, communities undertake with the intention of enhancing health, preventing disease, limiting illness and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals'⁴. In the UK, self-care is a core principle of services for people with long-term health needs and emphasizes greater control, autonomy, and choice over care. Although practicing self-care is primarily an individual responsibility, a patient perspective on self-care emphasizes the role of health services in supporting people in taking care of their health: 'The NHS cannot do self-care to people, but what it can do is to create an environment where people feel supported in self-care'^{5,6}.

Most routine daily activities could be described as self-care; for example, brushing our teeth, having a warm bath, exercising frequently, eating nutritious food, reading a book, and going for walks, are activities that many people engage in which have a positive impact on their mental and physical health. However, at times, various issues (such as

physical illness, social problems, and mental health problems) may prevent people from practicing self-care; therefore, receiving support from friends, relatives or health professionals and services is important in order to be able and motivated to take care of our health. As a result, individuals and/or families often seek support from healthcare professionals (e.g. doctors, nurses, allied health professionals, and pharmacists) to help care for them or a loved one.

Promoting the idea of self-care to service users has been found to have a positive impact on both the service users and services⁷. It has been suggested that supporting self-care can lead to improved health and quality of life, increased patient satisfaction, and reduced use of services, including fewer primary care consultations, reductions in visits to outpatients and A&E, and a decrease in the use of hospital resources. With regards to the impact of self-care on patients, it has been proposed that self-care can lead to better symptom management (e.g. reduction in pain), improved feelings of well-being, increased life expectancy and increased quality of life with greater independence. Regarding the impact of self-care on care services, it has been proposed that if people practice self-care, then visits to GPs could decrease by 40%, outpatient visits could be reduced by 17%, A&E visits could be reduced up to 50%, and hospital admission could be halved⁸. It appears that the concept of self-care therefore aspires to improve patients' overall health and well-being by promoting choice, control, and autonomy, while alleviating some of the pressure on health services from treating an increasing number of people with long-term health problems.

4.2. WHAT IS SELF-CARE IN MENTAL HEALTH?

There is still a lack of clarity around what the concept of self-care includes in relation to mental health, and what activities should be regarded as constituting self-care⁹. The use of concepts such as self-help, self-management, and recovery which, like self-care, highlight patients' autonomy and control over their treatments, care and lives, complicates the development of a definition of self-care in mental health. Self-help approaches in mental health often involve low intensity formal interventions, such as computerised Cognitive Behavioural Therapy (CBT) or guided self-help (both recommended by the National Institute for Health and Clinical Excellence [NICE]), which are provided by the Improving Access to Psychological Therapies (IAPT) services. Self-management is a concept that has been used mainly in the context of managing long-term health problems and has contributed to the development of initiatives that embed self-management support within healthcare services¹⁰. From a mental health perspective, self-management includes "whatever we do to make the most of our lives by coping with our difficulties and making the most of what we have"¹¹. Whereas self-management emphasizes the strategies that people use to manage their health problems, self-help refers to the more structured, professionally-led interventions. Finally, recovery is a term that emphasizes the empowerment of individuals to live meaningful lives and have a more positive outlook on restoration, despite experiencing a mental health problem⁹. Recovery in mental health is often defined as both personal and clinical. Personal recovery includes people having meaning and quality to their lives, whereas clinical recovery refers to a reduction or absence of symptoms (frequently to a level below a clinical threshold)³.

4.3. SELF-CARE IN PRIMARY CARE MENTAL HEALTH

Between 1 in 6 people in Essex will suffer a mental health problem in the course of this year¹² (whereas in England the number increases to 1 in 4). The number of people with a mental health diagnosis is expected to increase, and therefore, the demand for mental healthcare is predicted to increase¹³. Whilst the demand for mental health care increases, austerity measures imposed by the Government have placed an unprecedented pressure on mental health services¹⁴.

In order to manage the demand for (mental) health care more efficiently, managed health care systems, such as the UK National Health Service (NHS), have been encouraging people to practice self-care with a view to reducing health service costs and empowering people to take responsibility for their health and care, often with limited support from services and professionals^{15 16}. Self-care interventions for the management of long-term health (e.g. cardiovascular disease, diabetes) and mental health problems (e.g. anxiety, depression, bipolar disorder, schizophrenia) have been proposed as convincing alternatives to professionally-led care in order to improve peoples' quality of life and confidence and reduce the use and therefore the cost of healthcare services¹⁷. The evidence base, with regards to the effectiveness of supporting self-care for mental health problems, tends to be primarily based on clinical trials using professionally developed self-help interventions for mild to moderate common mental health problems which draw on CBT principles. These can be administered or delivered with limited therapeutic contact, including audio-tapes, computer packages, literature and treatment manuals^{18 19}.

³ In this report when the concept of recovery is used alone, it includes both the clinical and personal dimension.

Primary care mental health in England is organised around General Practitioners (GPs) and IAPT services. In addition to providing care for physical health problems, GPs are also responsible for providing care and treating adults suffering from common mental health problems (CMHPs) (i.e. anxiety and/or depressive disorders)²⁰. Previous research has shown that only a proportion of adults suffering from a CMHP will seek to access their GP, and of those that do, a smaller proportion will receive a diagnosis²¹. GPs have been criticised for either failing to recognise (particularly in its mild or moderate form)²² or for over-recognising²³ the presence of a mental health problem. The disputes over the presence of a mental health problem in a patient illustrate that the concepts of mental health and illness are contested and not well defined^{24 25}. Further research is needed to understand how people perceive these concepts. Research on the interactions between GPs and patients on mental health-related consultations has suggested also that there are a range of patient and GP-related factors that hinder the recognition of a CMHP, such as the presentation of patients' symptoms and GPs' avoidance of making a psychiatric diagnosis²⁶.

Although GPs deal with the majority of patients who present with a CMHP in primary care settings, their training in mental health is often inadequate for the number of patients they see and much less than the training other specialist professionals receive (i.e. mental health nurses)^{27 28}. GPs' training is based mainly upon a bio-psychosocial model of illness²⁹, which takes a holistic approach to patients' mental health needs by attributing the causality of mental illness to the interplay between biological, social and psychological factors. Frequently, though, GPs are not trained to provide psychological therapies to patients. Nonetheless, scholars have argued that GPs can offer much needed practical

advice and support to patients with CMHPs, simultaneously balancing the roles of friend, therapist, and clinician²⁶.

In order to enable provision of NICE recommended psychological treatments as a first-line treatment option to patients who present in primary care with CMHPs, the Department of Health established IAPT services in 2008³⁰. IAPT offers primarily short-term CBT, which is a psychologically-based intervention that explores patients' cognitions and their effects on confidence and self-esteem. Depending on the level of need, CBT may take the form of self-help tools, bibliotherapy, telephone or computerised therapy; or face-to-face group or individual therapy (usually from 6 to 20 sessions)⁴.

Although patients may refer themselves to an IAPT service, access to these services is filtered by an initial telephone assessment process based on the application of diagnostic criteria³¹. Patients that do not meet the criteria, have co-morbid disorders (e.g. substance misuse problems), are considered severely ill or at risk to themselves or others are usually excluded from IAPT services at the point of assessment and may not receive any treatment at all since community mental health teams (and other secondary care services) have high thresholds for patients with complex, though not the greatest (e.g. psychosis, schizophrenia), needs. This care gap has been well recognised for years, but IAPT does not fill it³². A large proportion of these individuals have complex and significant mental health needs³³, and as such, the way that services are organised and delivered fail to meet their needs³¹. Additionally, the rise in the prescription of anti-depressant medication, despite the establishment of IAPT services to offer more choice in treatment, indicates that accessing psychological treatments remains a challenge³⁴.

⁴ One of the major criticisms of IAPT is that is mainly focussed on delivering CBT based treatments.

4.4. PRIMARY CARE MENTAL HEALTH SERVICES IN ESSEX

Healthcare in Essex is partly the responsibility of seven clinical commissioning groups: Basildon and Brentwood, Mid Essex, North East Essex, Southend, Castle Point & Rochford, Thurrock, and West Essex. Currently NHS England is the primary commissioner of GP services; however, from April 2015 many CCGs started to take on more responsibility for commissioning general practice in their area. Across Essex there are approximately 252 GP practices.

IAPT services in Essex are commissioned and delivered by two NHS foundation trusts; the Essex Partnership University NHS Foundation Trust (EPUT)⁵, which is responsible for the South Essex region, and the Hertfordshire Partnership University NHS Foundation Trust, which is responsible for West Essex (Healthy Minds), Mid Essex, and North East Essex (Health in Mind)⁶.

4.5. KEY ISSUES

Despite the significant potential of self-care to assist those who experience mental health difficulties, key issues about what forms of support should be made available across Essex to assist them remain. For example, how do people living in Essex who have received a diagnosis of anxiety and/or depression perceive self-care? What do they understand by self-care? How do Essex-based primary care services support people to practice self-care in mental health? This research project aimed to address these questions.

⁵ On the 31st of March 2017 the South Essex Partnership University NHS Foundation Trust (SEPT) and the North Essex Partnership University NHS Foundation Trust (NEPT) were merged to form the Essex Partnership University NHS Foundation Trust (EPUT).

⁶ Currently, the "Essex, Southend and Thurrock Mental Health and Well-Being Strategy 2017-2021" is being developed to facilitate collaboration and joint work between services across Essex.

5.0

Methodology



5.1. ETHICAL CONCERNS

All health-related research is reviewed in advance by an independent group of people called a Research Ethics Committee to protect the safety, rights, wellbeing and dignity of the participants. This study was reviewed and given a favourable opinion by an NHS Research Ethics Committee (REC York 16/NE/0260) and the Health Research Authority. It also received approval from the local Research & Development office (Central and North West London NHS Foundation Trust). All participants provided their informed consent, and they were briefed about issues of confidentiality.

5.2. HOW DID WE APPROACH AND SELECT PARTICIPANTS?

Our aim was to collect the views and experiences of a diverse range of people, irrespective of their health service use and technological dexterity; we thus employed

a variety of methods to approach people to take part in the group discussions across Essex. Below we present the methods that we used to approach and recruit participants.

1. We placed posters inviting people to take part in the study in locations where IAPT services were delivered.
2. We used Healthwatch Essex's social media accounts (e.g. Facebook/Twitter) to inform people about the study and invite them to participate.
3. We used a variety of local newspapers to advertise the study.

Owing to the diversity of the methods that we used to approach and recruit participants, we developed a set of inclusion and exclusion criteria. Table 1 presents the inclusion and exclusion criteria for our study. The application of these criteria ensured that we had selected the right sample of people to participate in the group discussions.

TABLE 1. INCLUSION AND EXCLUSION CRITERIA

INCLUSION CRITERIA	EXCLUSION CRITERIA
18 years of age or older	Below 18 years old
Received a diagnosis of anxiety and/or depression (at some point in their lives)	Unable to give informed consent
	Unable to understand or speak English
	Received a diagnosis of schizophrenia, bipolar disorder, psychosis

5.3. HOW DID WE COLLECT PARTICIPANTS' VIEWS AND EXPERIENCES OF SELF-CARE?

We took a 'deliberative democratic' approach to consulting the public about their views on self-care in mental health. Deliberation 'refers either to a particular sort of discussion - one that involves the careful and serious weighing of reasons for and against some proposition - or to gain an interior process by which an individual weighs reasons for and against courses of action'³⁵. Deliberation is a participatory approach that involves collective problem solving discussion which facilitates individuals from different backgrounds, persuasions, and values to listen, discuss, understand, potentially persuade, and finally come to informed and public-spirited decisions^{35 36 37}. The decisions and the process through which these decisions are made are underpinned by a commitment to civil engagement, which promotes people's involvement in the decision-making process for topics or issues of interest. In addition, deliberative approaches have the potential to improve governance, as they foster collaborative problem solving among citizens, communities, and organisations³⁶.

Deliberative methods have been increasingly used in the health sector³⁵. In the UK, the NHS has been employing deliberative methods to elicit public views in setting health care priorities³⁸. Mail surveys³⁹, interviewer-administered surveys⁴⁰, the citizens' jury⁴¹ and deliberation-orientated focus groups⁴² are some of the deliberative methods that have been used in health settings. Factors assisting with introducing deliberative methods are gaining impetus in the health sector, and include improving the public's understanding of complex health care issues, stimulating debates, and aligning public and community values for health services priorities³⁶.

In this study we employed the method of deliberation-orientated focus groups to gain an in-depth understanding of people's views on self-care in mental health and how primary care mental health services support them in practicing self-care. Owing to the essential role of the individual in the practice of self-care coupled with the complexity that surrounds the topic within the primary care mental health context, the deliberative-orientated focus groups resonated well with the aims of the study. For instance, the groups gave the opportunity for participants to discuss self-care related issues in-depth and develop their views during the group discussion⁴¹.

At the end of the group discussions, participants were also asked to complete a short questionnaire which included a few demographic questions, such as age and sex.

Three group discussions were held in different locations in Essex during January 2017 with a total of 12 participants (9 female and 3 male); Chelmsford (5 participants), Harlow (3 participants) and Rayleigh (4 participants).

The average age of participants was 54 years (age range 39-70). All participants had at some point received a diagnosis of anxiety and/or depression. The majority of participants (8 out of 12) had been prescribed medication; a small proportion reported that they were also receiving private counselling.

Participants received a £20 voucher (plus travel expenses) as a thank you for taking part in the group discussion.

6.0

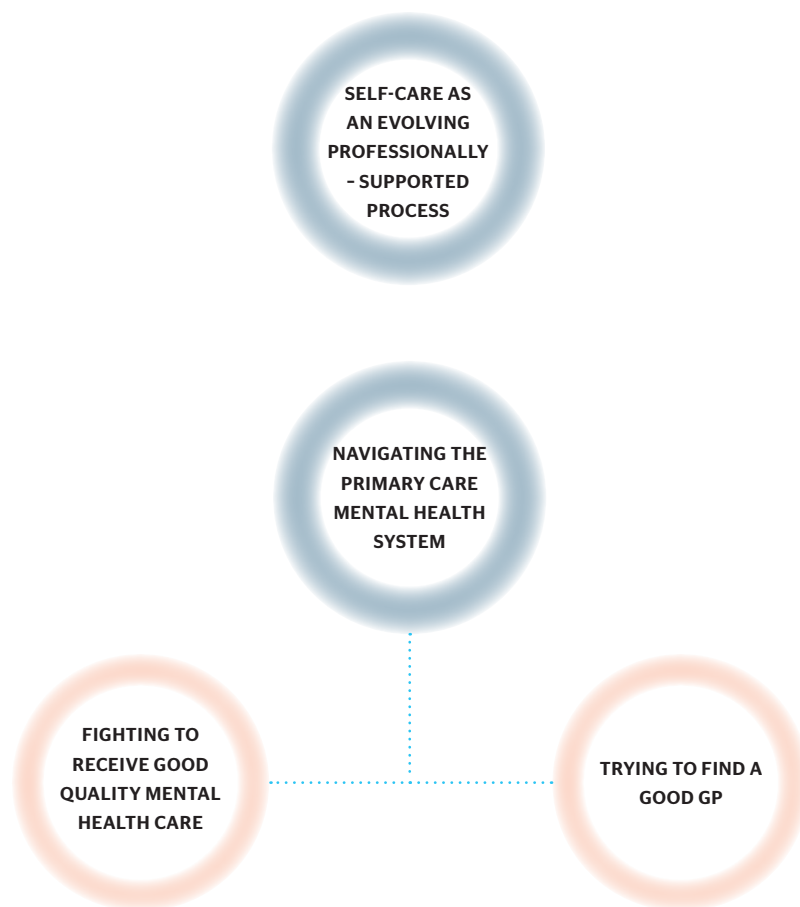
Analysis



We analysed the collected data using a qualitative method of analysis called 'thematic analysis'⁴³. The analysis of the group discussion resulted in the development of two themes (and two sub-themes) that describe how participants

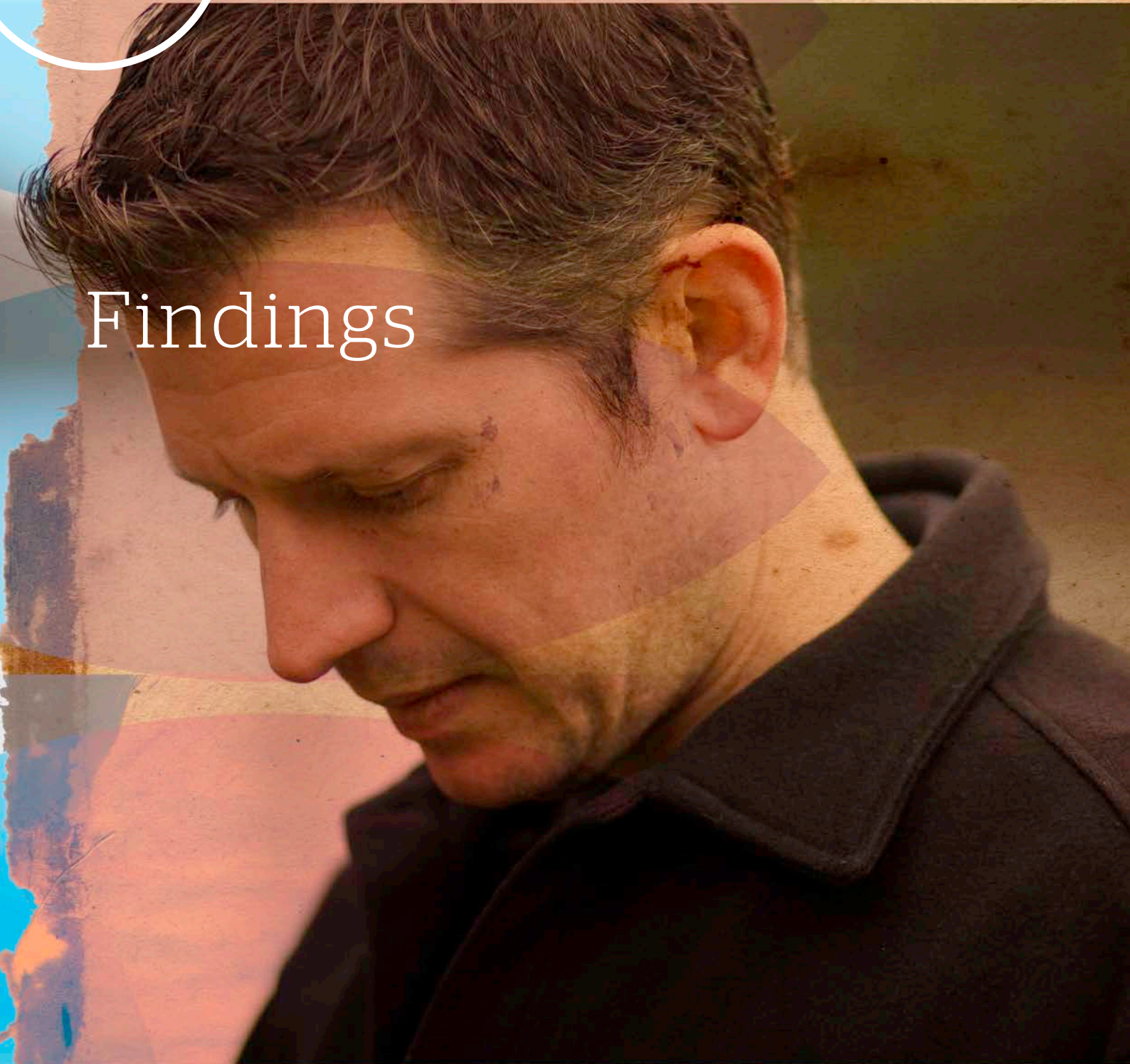
viewed self-care in mental health, and how primary care mental health services supported them in practicing self-care. Figure 1 presents the themes and how they relate to each other.

FIGURE 1: THEMES AND SUB-THEMES



7.0

Findings



Participants described self-care in mental health as a continuous process, whereby performing and combining self-care activities in their daily lives with the consistent support of health care professionals, helped them maintain positive mental health, manage symptoms, avoid relapse and promote recovery. Participants reported that setting up a structured routine was a central process in self-care which assisted them with better managing and having more control over the mental health condition and over their lives in general. Within this context, participants also viewed self-care in their lives as a transaction; they practiced self-care by engaging in a range of activities, to avoid mental ill health. Receiving professional support, even during periods where participants were not feeling emotionally distressed, played an important role in their ability and motivation to practice self-care in their mental health. However, the majority of participants reported difficulties with access and continuity of care, and problematic interactions with GPs. Such difficulties negatively affected their ability and motivation to self-care, and hence, had a negative impact on their mental health and vice versa.

7.1. SELF-CARE AS AN EVOLVING PROFESSIONALLY-SUPPORTED PROCESS

Participants' level of functioning and experiences of distress appeared to influence the way they defined self-care, the activities that constituted their self-care routine, and the ways these related to the professional support they received from services. There appeared to be a consensus around the important role that professionals and services play in supporting people to practice self-care, particularly during periods of distress.

The ways that participants viewed self-care appeared to be influenced by their experiences of distress and level of functioning. Participants viewed self-care in mental health differently when they were experiencing periods of distress and when they were in recovery.

“No, I think when we’re in our period of feeling depressed or the bad times, we don’t do anything, very little. When we’re on our recovery, we start putting things that we’re trying to help ourselves get better. But when we’re in the low time we don’t do anything to help ourselves. We need the help to get out of that low period.”

During periods of recovery, participants viewed practicing self-care in existential terms, that is they defined it as a process through which they tried to understand themselves, improve their quality of life, and protect and safeguard their emotional and mental well-being from situations and interaction that could negatively affect their mental health.

“I think for me self-care at the moment is . . . something I don’t always know. Knowing my limitations, knowing what I can cope with and can do. Because quite often I’ll try and do what everyone else is doing and what I expect I should be doing or what I think I should be doing and it’s too much. And then it, you know. So, I think, yes, for me it’s just being able to hear myself and to know what I can do and what I can’t do and what I’m capable of. And it’s quite hard to know that. Because sometimes you just think “I can do what everyone else is doing.”

Understanding their abilities and personal limits, as well as being able to reflect on their actions and emotions were described as important aspects of self-care.

“You always have to ask yourself “Does what I’m going to do, will it serve me? Will it actually serve me?” And then you do have to answer that question yes, okay we go for it or no, okay we back off. So, I think that’s an element of self-care that we all adopt as well.”

In contrast, participants reported that, during periods of distress, they viewed practicing self-care as a target or task; that is, being able to self-care indicated that their mental health was improving.

“Personally speaking, they [performing self-care activities] would be seen as an achievement, “I’ve managed to get out, I’ve managed to interact and I haven’t upset anyone so it’s all good.”

Noticeably, many participants were aware of the effects of their actions on their social networks; not causing emotional harm to other people while they were trying to achieve their self-care target was an issue that appeared to influence how they viewed self-care in mental health and whether they would practice it or not.

Participants reported that performing a self-care activity infrequently, such as going for a walk once per month, had limited potential to have a positive impact on their mental health. In contrast, they reported a more positive impact when they had managed to view and incorporate the self-care activity as a part of their daily routine, such as going for a walk every two or three days.

“But I found, and again only recently, that the only way that I seem to be able to make sustained changes, as opposed to periodic tidy-ups as you describe, is by building something into a routine.”

Similarly, another participant commented:

“The main thing is routine. I mean you’ve started to take me now on short walks to try and get me to walk a lot easier, because I have very swollen feet. So, we do that once, maybe twice a week, but we try and do it once a week, not far, because I can’t go far.”

Participants reported that setting up and maintaining a routine empowered them and assisted them with being in control of their mental health, which also included more effective managing of distress, such as sadness and worry. They commented though that to be successful, this routine needed to be based upon realistic and feasible targets. Participants reported that setting up realistic expectations of themselves in relation to self-care was key in order to be in a state where they could take care of their mental health.

“There is a fine line, isn’t there, between setting your sights high and then . . . Say, “I’m going to go and do exercise every day” that’s a really hard thing to do but then if you don’t do it, which you’re probably not going to do it every day, you’re then going to feel like you’ve failed. But then if you say to yourself, “I’m only going to do it once a week” then you’re going to achieve it but it’s not really enough. So, it’s hard to find that. Again, everybody’s individual.”

Being able to successfully accomplish their self-care targets was described as empowering, and therefore, had a positive impact on participants’ self-esteem and confidence.

“But it’s also empowering. In terms of what a friend has said, and I think that, again, this varies, but if you’ve got that awareness and you recognise that some days it’s going to be easier or harder, setting yourself reasonable challenges and reasonable objectives . . . ”

Participants talked about a variety of activities that they tried to routinely perform in order to improve their mental health and/or avoid mental ill health; taking care of their personal hygiene and physical appearance, performing and being involved in outdoor and indoor activities, such as exercising or cleaning their house, as well as interacting with friends and family were examples of self-care activities that participants talked about during the group discussions.

“Well, you might like drawing, painting, you might like making things. You might like to do that walk in the fresh air that will do you good. You might like to go with a friend or your pet or something, because it does - doing the indoor/outdoor things does make you feel good. And sometimes you don’t necessarily want to do it on your own. You might want to do a relaxation group or something.”

Other participants expressed a similar view:

“Go for a run, go for a walk, go in the park, do painting, drawing, exercise, gym, do what you want to do that makes you feel good . . . ”

“And externally our self-care is that we wash our hair, we try and look good, we try and dress properly. That is the self-care that we need in order to present that to the outside world.”

Participants reported a variety of factors that prevented them from engaging with and practicing self-care in mental health, such as physical health and social problems. Financial difficulties, loneliness, and social isolation were examples that participants used to illustrate how social problems influenced their ability to practice self-care. For instance, a participant commented on how financial difficulties can prevent people from taking care of their mental health.

“Yes, I think if people are short of money it limits their . . . I’m not saying there aren’t things that they can do, but it’s more limited. If people can’t travel, if they haven’t got transport of some sort, then they can’t go out very far. If they’ve got health problems as well as mental health problems that also means that they’re limited in what they can do.”

Loneliness was another issue that appeared to influence participants’ ability to be in a state where they were able to practice self-care.

“I live on my own so that’s quite a big factor. It’s like it’s entirely up to me to do it, I haven’t got anyone saying, “You’ve got to get up.” It’s always me that’s telling myself to do stuff.”

Almost all participants reported that when they were not able to practice self-care, they experienced feelings of stress and worry.

“So, I’m sort of having a stress about it. And if I don’t go to the gym I feel very guilty. And very cross with myself. Because I know that if I go to the gym, if I exercise, it just helps keep me going. So, if I don’t do it, I do get stressed about not doing it.”

This quote illustrates the important role that self-care played in participants’ lives and the confidence it gave them to be in control of their mental health.

However, a few participants talked about their efforts to hide their mental health difficulties, in order to present as ‘normal’ to the outer world.

“You have to have a mask, in other words. In order to survive. You need to work, you need to present an outer image to people that you’re okay and that everything you do is okay. It’s a struggle. That is a real struggle all the time, isn’t it?”

Participants reported that going in and out of the masked role was a strenuous activity, which nevertheless, assisted them to survive living with a mental health condition; it also had negative effects on participants' self-esteem and confidence.

“I think we have lots of faces depending on who we're with and the sort of impression we want to give to those people. In a sense, you lose the sense of who you are, because you have to keep changing yourself all the time. And that's very disruptive for your own self-esteem and your own confidence.”

The fact that participants had to hide their emotional distress and struggles with mental health, is an indication of the stigma that surrounds mental illness.

Almost all participants reported that health care professionals and services play an important role in their ability and motivation to practice self-care. Interestingly, participants reported that they expected a different level of support from their GPs during periods of distress and during their recovery; in the first instance, they reported that they expected from their GPs to be actively involved in supporting them by giving them advice, making onward referrals, and listening to their concerns. In the second instance, they reported that they expected from their GPs to monitor their progress, and provide them with reassurance that their recovery was progressing well. In both instances, participants considered their interactions with services and professionals as an integral part of their self-care in mental health.

“You cannot have the medical involvement without the self-care, unless you strap people down and force them to do it.”

Another participant explicitly linked the act of visiting her GP to practicing self-care in mental health.

“I go to my GP because that is self-care.”

Participants viewed their interactions with services and professionals as a self-care activity, particularly during periods of distress.

“And you want someone that's going to give you advice and say “Have you thought about this? Have you thought about that?” or make a decision for you and phone your GP, or somebody that's going to take some action for you. Because sometimes you don't know what to do for the best. You want someone else to take that out of your hands, sort it out for you and give it back to you.”

Similarly, another participant commented:

“Sometimes you can wake up in the morning and you just think, ‘I can't be dealing with this world.’ Throw the duvet back and stay the whole day in bed and feel sorry for yourself or whatever the case may be, but you might not want to go and walk or you might not want to - you might need encouraging or somebody to hold your hand.”

Being monitored and receiving reassurance from health care professionals, during periods of recovery, was described as a positive action that contributed to their ability and motivation to practice self-care.

“But then what I think can happen quite easily, and this can happen with both cancer and mental health or anything, let's say you're going along and it's six months, nine months, a year, and then one day the GP goes, “Do you know what, you're getting on so well I don't want to see you anymore.” Then what happens is after a year or so that person then develops cancer again and it goes unnoticed because they're not getting monitored, or

if they've got mental health problems they start slipping into depression, they're then in crisis and you have to start again . . . instead of it being gaps."

Similarly, another participant commented:

"So, in my own situation, over the last year I've been seeing my GP roughly every three months. I saw him just before Christmas and he said, "Unless you have any problems I don't want to see you for six months." Right? I take that as a signal of my GP's confidence in me that I'm looking after myself well enough that he doesn't want to check up on me for another six months. But it's couched with the "Unless you have any problems", which is giving me that safety net knowing that he's happy with me, happy enough with me that he doesn't want to see me for six months. But he's also saying, "This is the reassurance." He's also saying, "If you have any problems come back and see me."

Noticeably, participants emphasized the role of healthcare professionals with regards to how they viewed self-care in mental health. Participants not only expected to receive support from services and professionals when they were experiencing periods of distress; they also expected to receive support during their recovery. This type of support appeared to serve mainly as reassurance that participants were heading in the right direction with regards to improving their mental health.

7.2. NAVIGATING THE PRIMARY CARE MENTAL HEALTH SYSTEM

The majority of participants had had a diagnosis of anxiety and/or depression for several years, and therefore, they had several years' experience interacting with mental health services and professionals in order to treat or avoid mental ill health. However, all participants reported difficulties trying to access services and receiving professional support either during a period of distress or during their recovery.

7.2.1. FIGHTING TO RECEIVE GOOD QUALITY MENTAL HEALTH CARE

All participants linked self-care in mental health with receiving consistent support from primary care mental health services, and in particular GPs. Hence, being able to access high quality mental health care and support contributed to positive mental health. However, all participants described receiving good quality mental healthcare as difficult; participants cited problems with access and continuity of care, and described them as issues that negatively affected their mental health. A large proportion of participants were very unhappy about the time limited, delayed, and inconsistent support they had received from primary care mental health services.

Participants described problems with accessing mental healthcare as an issue that had a negative impact on their ability and motivation to self-care. Some participants reported that they had difficulty accessing services because they did not know what services were available in their locality, and/or the service that they were told that they needed was not available. They described the current configuration of the primary care mental health system as badly advertised, and therefore, of limited use as they were not aware of the services available in their local area.

"There needs to be more advertised I think, in mental health, that there is help available and where you will find it . . . [name of participant] didn't even know that there was help. He didn't know that you could and get help. Where do you go? He didn't know."

Another participant talked about the limited availability of services in his local area:

“So, for example, I know of people who’ve been told by a professional that they need, for example, an anger management course, and they agree, “Yes, that sounds a great idea” but there isn’t one. So, it’s very disheartening to be told, “You need to go on this” but it’s not actually there so you can’t actually go on it. Then, again, you’re being let down and that adds to your stress.”

Noticeably, problems with service availability appeared to have a negative impact on participants’ mental health; they reported feelings of disappointment and frustration with being ‘rejected’ by services. Long waiting lists to access a service was also a factor that appeared to have a negative impact on participants’ mental health, which, therefore, affected their ability to practice self-care, and vice versa.

“And waiting lists that you’re put on to be told 18 months later that you’re not on the waiting list and it’s just pie in the sky and you’re not going to get anything.

It makes you feel really valueless, like you’re not worth the trouble.”

Another participant reported that he had been waiting to access a service for over four years; he said he felt ignored by these providers.

“It would be nice if there was actually somebody who would do the courses that I keep getting promised. I’ve been promised courses for the last four years and they’ve never appeared. I’ve waited a year now for the last therapy sessions I was promised, and I’m still no further on. They’ve given me no date of when I’m going to get it, or if I’m going to get any therapy, I’ve basically just been ignored.”

However, even when services were available and participants were aware of them, they reported a variety of obstacles that stood in their way of receiving mental health care. Experiencing and trying to overcome these obstacles also had negative effects on participants’ mental health. Some participants reported that they had problems with accessing care because they did not meet the criteria of that service.

“And the criteria for that is not good either. So even if you can find a service that’s got a place in it you can’t necessarily get on that if you don’t fit their criteria.”

These participants reported that being ‘rejected’ by services was another instance where they experienced rejection in their lives which contributed to the perpetuation of a negative self-image, and therefore, negatively affected their mental health. Other participants linked their difficulties accessing a mental health care service to the risk-based focus of mental health services. These participants reported that they had previously been ‘rejected’ by services because they did not present a significant enough risk to themselves or others.

“But I know from experience, as much as I respect them, that ringing and having a chat to friends or the Samaritans isn’t going to help me right now. I’m not suicidal, I’m not a risk to myself or anyone else, so I don’t need to ring 999 and there’s no point in me going to A&E. If I go to A&E and they say, “What’s the problem?” “I’m having a depressive episode” eventually someone’s going to turn around and say, and not necessarily in these words, but they’re going to ask questions to ascertain whether I’m a risk to myself or others and if the answer to that is no they’re going to say, “Go and see your GP on Monday morning.”

Delays with accessing care was putting at risk participants' mental health, and therefore, ability to be in a state where they could practice self-care. The long gap between asking for help and receiving professional support had often contributed to poor mental health.

“That’s the thing, it’s the delay with everything that really, really just blows . . . time is a major contributor to problems. It’s the space between help. It just needs to be addressed, it really does . . . you see the problem there is from 7:15 on a Friday night until Monday morning when you go and see your GP, if you can get an appointment, the illness is then starting to take hold.”

Participants reported that by receiving timely access to primary care mental health services it could help them to prevent any further deterioration of their mental health and also contribute to developing more efficient self-care techniques. Such self-care techniques could contribute towards improving their coping skills.

“Especially when people experience things like bullying or they come from a problem house there should be counselling available immediately, not a long wait. It would save money in the long run if people got help quicker and we’re taught, like you say, ways of coping with different problems.”

Noticeably, participants linked service availability with the financial pressures that the NHS has been experiencing over the last few years. Within this context, some participants described how financial constraints impacted their recovery:

“I don’t know if [name of participant] had help a little bit, but myself, I’ve had help on a couple of occasions. But then it just stopped, because, “Sorry, we have to stop these sessions. No more funding.” Or the social [side of health] is now being disbanded or

whatever the case may be. There’s just not enough help out there.”

The quote presented above illustrates how external factors, such as funding arrangements, influence the care that patients received, which negatively affected their ability to practice self-care, contributed to poor mental health, and interrupted their recovery journey.

Another issue that participants talked about during the group discussions was the limited, inconsistent, and sometimes inappropriate support they had received from services. Although participants often valued the support they had received from services, many of them felt it was insufficient. These participants were critical of the low number of sessions they were offered (e.g. counselling or CBT) and the minimal follow-up support they received after the end of the block of the sessions.

“The majority, 99% I would say, of people don’t know that there’s help out there and they try and do the best that they can do themselves, because trying to get help for mental health is really, really hard and if you do get something it’s only for a short time and then they say, “you’re at the end of it” and then where do you go from there?”

Similarly, other participants commented:

“The biggest problem is even if you do get some help it’s for a limited amount of time, it’s not ongoing, and then sometimes the help that you’re getting is not always the most appropriate.”

“That is where the biggest problem lies. It’s because there is no consistency whatsoever in any of the mental health care, none.”

“You used to get a lot from GPs because GPs had got to know you, then you’d go and see them, they’d have a chat with you, they had time, “How are you getting on? What’s going on in your life?” and that sort of thing. I think, even when I was in my 30s GPs still had time to do that, now you just don’t get that at all. There isn’t really anybody else available that you can ask for help, unless you’ve got some really clever friends or something.”

Owing to the difficulties they had faced trying to access mental healthcare, many participants reported that they had either decided to seek help from friends and/or relatives, use their own (often limited) resources to manage their symptoms and improve their mental health or when possible, seek support from professionals working privately.

“But the reality was, and this I do find quite frustrating, that without paying to see a professional therapist I did what most mental health professionals would say you should never do, I pulled myself together, “I’m not going to get what I feel like I need so it’s sink or swim time. So, I’ll stop thinking about crap, struggle on, keep taking the tablets” and fortunately there was no major disaster that occurred.”

Other participants reported that they had lost faith in the NHS to assist them with addressing their mental health needs.

“I feel I’ve almost given up now with thinking that anything could be any different in the NHS and I’m more of the opinion that we need to be making things happen for ourselves on a charity level.”

Similarly, another participant commented:

“I just don’t think that there’s anything in place really to take care of anybody mental health wise. It’s completely and utterly down to the individual going and asking for help. There is nobody there, as a catch net if you like, to say, “Oh look, you really need some help, can I offer you this help? Would you like to try that?” There just isn’t anything like that in place.”

Although receiving professional support appeared to be an important component of participants’ structured routine of self-care in mental health, problems of access and continuity of care prevented them from receiving it.

7.2.2. TRYING TO FIND A GOOD GP

Participants described their general practitioners as important contributors to their mental health care and a potential source of advice on self-care. However, a large proportion of participants reported a variety of difficulties when interacting with their GPs. These difficulties included GPs’ lack of skills in providing good mental healthcare, the short length of the clinical consultation, and problems with getting timely access to a GP. Many participants described themselves as lucky for having a GP who is empathic and understands their mental health needs, and is also willing to make onward referrals to other mental health services.

For many participants receiving mental healthcare from trained and skilled professionals played an important role in their mental healthcare and ability to self-care.

“It’s not just about someone to talk to either, that person has got to be knowledgeable, they’ve got to be trained, they’ve got to be able to really do something. It’s no good just going to talk to the nurse, that is not going to solve everybody’s problems, it might do in one or two.”

However, a large proportion of participants reported that they had frequently consulted GPs who believed that they were not trained and skilled in providing mental health care or self-care advice. Participants commented that GPs need to receive more training in order to be able to identify people who experience emotional distress, and give advice on self-care in mental health. Some participants appeared to believe that only mental health specialists were able to listen to their concerns and provide mental healthcare.

“The GP is not set up for that [listening to patients’ concerns and giving self-care advice]. If you go to somewhere like [name of hospital], the doctors you see there are trained in mental health and they will have all those conversations for you and explore all the issues.”

Many participants believed that GPs were inadequately trained in delivering mental healthcare:

“And I also think that a lot of GPs think they know it because they’ve done their block of training around mental health. Which is often not enough.”

There was a consensus across the groups that GPs should receive more and better training in providing mental healthcare.

“I’d like to see that more of the professionals have got a broader training. For example, the GP should be trained in ways to care for people, understanding of mental health and understanding of learning disability, and the common people who come into mental health problems.”

Similarly, another participant commented:

“... and a little bit of training on how to deal with and know what to do with mental health. Doctors need to be trained in mental health and what to do and they should know where to send you for help if they cannot help you themselves.”

Participants also commented that often GPs were eager to prescribe medication, avoided listening to patients’ mental health concerns, and were not willing to engage with patients on a level where they could feel comfortable talking about their mental health needs.

“When you go in there - I’m going back a long time ago, when you walk in the room, they’ve already got the prescription... They’re not focusing on what you’re saying sometimes.”

Although some participants drew upon their past to illustrate their negative experience when interacting with their GPs, other participants had more recent experience of receiving poor mental and physical care.

“The doctor I’m supposed to be seeing, one day I walked in there and I wasn’t feeling very good and my back was in spasm and I could hardly move and I went in there to see him and he said to me, “Lose weight, you’re too fat.” I walked out of there crying and we do have a lady doctor, so I always make my appointments to see her...”

Many participants described their interactions with their GPs as unhelpful because they neither helped them to address their mental health needs, nor assisted them with practicing self-care. Participants reported that even if GPs had not received any mental healthcare training, they should have been at least empathic to the issues they were bringing to their encounters. Some participants reported that, compared to male GPs, female GPs were more likely to be empathic and listen to their concerns. Noticeably, many participants described themselves as lucky for having a GP who acknowledged and understood their mental health concerns, showed empathy, and supported them with navigating the mental health care system.

“My GP as I said before, I’m very, very lucky but she is a rarity in what I think should be the norm. She’s just amazing, she’ll sit and talk to me about whatever I want and she actually takes longer than five or ten minutes with me and if I phone the surgery and want to speak to her she will phone me back whether she’s on call that day or not, whether she’s the one phoning back patients or not. She will take the time to do that.”

Participants reported forming strong therapeutic bonds with GPs who were willing to listen to their concerns and support them (either by acknowledging their concerns or making onward referrals to services), as well as shared-decision making. In these relationships, it appeared that participants were treated as equals and their opinions about their mental health and care were valued. Another issue that participants felt affected their interactions with their GPs was that they were not able to discuss more than one issue/concern during any one consultation, and not having enough time to talk about their mental health concerns at length.

“This is my fort and you’re not coming in. That’s what it feels like. They should be trained to a higher professional standard so they’re able to deal with people of all walks of life because that’s what they deal with. Because we are people from all walks of life. And the GPs need to be able to also have more time to spend with people”.

Noticeably, this quote illustrates how participants viewed the consultation room as an inaccessible place, where mental health talk was rarely allowed and facilitated. Another participant commented on how the one-issue-per-consultation limit affected how much time she could spend talking about her mental health concerns.

“The thing is you’re only given a five-minute appointment. In our GP surgery there’s a big thing, a big thing, one GP, one appointment, one condition.”

Some participants linked GPs willingness to gloss over their mental health concerns during the clinical consultation with their relative readiness to prescribe medication.

“Some GPs have absolutely no empathy and don’t have any clue at all. So, they’ll just keep stuffing you full of tablets which don’t do that person any good at all.”

These participants also linked GPs’ readiness to prescribe medication to the fact that they were a cheaper alternative to offering counselling or any other psychological intervention (e.g. CBT).

“The cynical head says “[name of participant], it’s money.” It’s all basically bottom line, it’s about money and funding. And it’s probably much, much cheaper to give somebody a tablet than to put them on once a week counselling.”

Taking prescribed medication for mental health problems was an issue of controversy during the group discussion. Whereas some participants were in favour of taking medication, and in some cases, they viewed them as a core aspect of their self-care routine, other participants reported a more negative view, describing them as addictive and unhelpful in addressing the roots of their emotional distress.

“I think on the medication, I kind of look at it slightly differently that I see if you’re on the right medication it can actually elevate you slightly to be able to help you deal with things better. So, it can be a tool, if you like.”

In contrast, another participant reported a more negative view of taking medication to address her mental health needs:

“No, I was on Sertraline, which is a drug they’ll put you on, I was on that for four years and that was no help whatsoever. I felt exactly the same on it as I did off of it. I was still depressed, the only trouble was when I was taking the medication I was too out of it to do anything about it. It just feels a bit like a chemical cosh, it’s just one of those things to keep you quiet. “Just sit him in a corner and he’ll be alright” and you’re not getting any healthier, you’re not getting any help, you’re not getting fixed, you’re not putting yourself right, you’re just, basically, wasting time.”

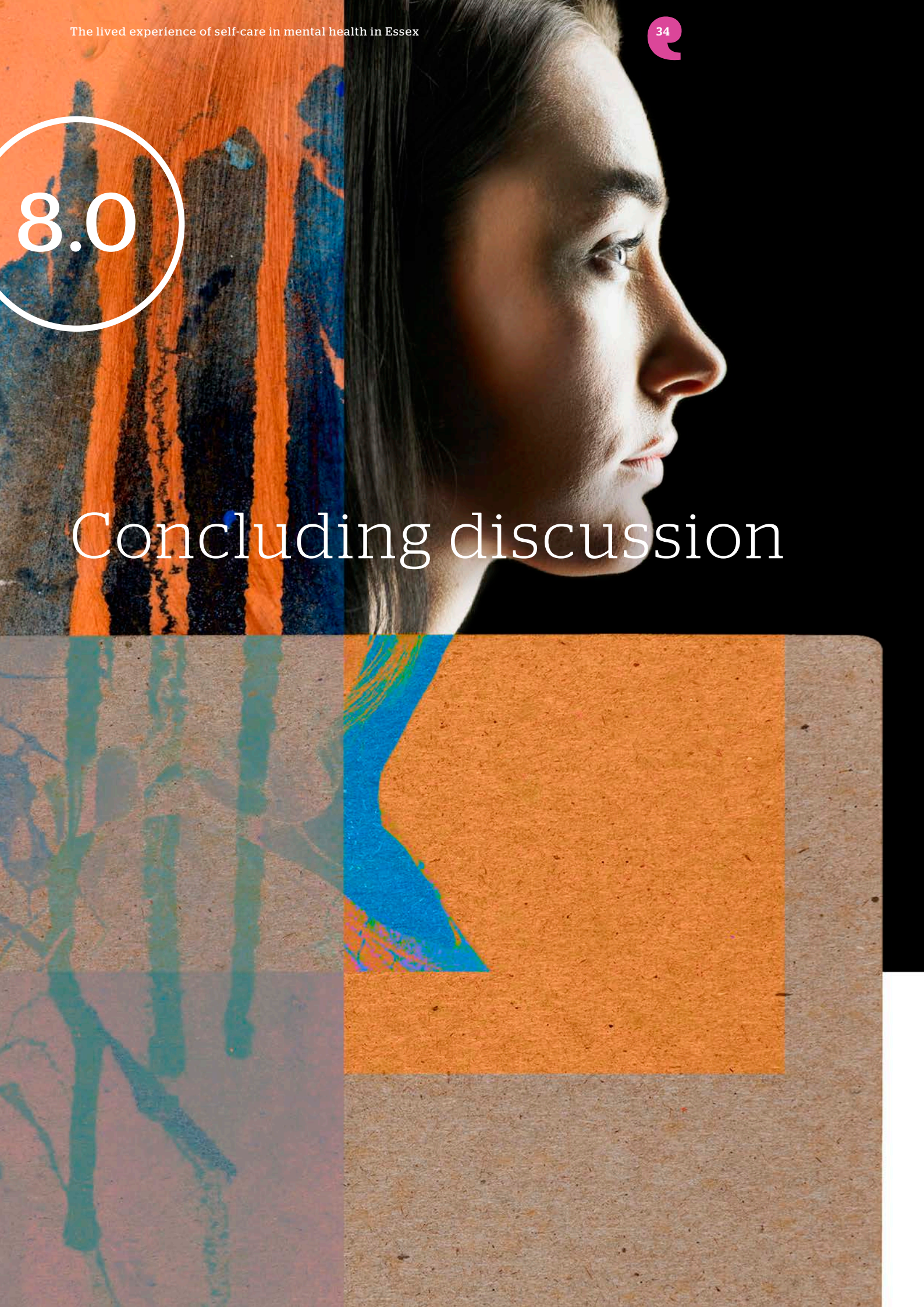
Despite their difficulties receiving good quality care, all participants reported that seeing their GP was an important self-care activity that contributed to their ability and motivation to take care of their mental health. As a result, despite their willingness to receive self-care support, participants rarely felt that primary care mental health services, and in particular their GPs, supported them in practicing self-care.

7.3. SUMMARY OF FINDINGS

The findings demonstrate that views of self-care and the activities that constitute self-care in mental health are not static; they change and readjust depending on the evolving condition of the person and changes in functioning. Consistent support from trained healthcare professionals coupled with timely and easy access to services that provide choice and respect patients’ pace towards recovery are key issues that enable and motivate people to take care of their mental health.

8.0

Concluding discussion



The aim of this study was to explore how people who have received a diagnosis of anxiety and/or depression view self-care and how primary care mental health services in Essex support them in practicing self-care in mental health. Our findings illustrate that self-care in mental health represents a unique experience for everyone, which changes and readjusts depending on the evolving condition of the person and changes in functioning. Participants reported a variety of activities that assisted them with taking care of their mental health. Receiving professional support was described as an important self-care activity and an integral part of self-care. Practicing and integrating self-care activities into a routine appeared to assist participants with maintaining control over their lives and mental health problems.

Our findings are in good agreement with other studies which have shown that people employ a variety of strategies to take care of their mental health, including employment, creative activity, physical exercise, healthy living, and structured routine^{11 44}. Many participants viewed self-care activities as a resource that contributed towards their recovery, and hence, they talked about how they contributed to regaining their sense of self and ability to live a normal life among normal people^{45 46 47}. Working, engaging and meeting with friends in the community were activities that appeared to promote a positive self-image that had positive effects on participants' mental health and motivation to carry on practicing such activities⁴⁸. Like other studies, our study has also shown the importance of control, including control over peoples' lives, treatment and management of symptoms in self-care^{49 50 51}.

The majority of participants reported difficulties with access and continuity of care; poor information about services, long waiting lists, limited choice over treatments, short duration of treatment, high threshold criteria and risk based assessments to access services. They also found service providers did not communicate sufficiently with each other and support from services was inconsistent; such issues contributed to poor patient experience and mental health outcomes.

Problems with access and continuity of mental health care is a persisting problem in the English mental healthcare sector⁵². For instance, as a quarter of adults with depression and anxiety receive treatment, most people with mental health problems receive no treatment at all⁵³. Although successive governments have committed to increasing the availability of psychological services (e.g. IAPT services), IAPT targets just 15% of those meeting service criteria for anxiety and depression. This is an important issue that needs to be resolved, taking into account the commitment of the government to ensure parity of esteem between physical and mental health services⁵⁴. To put this into context for physical health problems, if only 15% of patients diagnosed with cancer received treatment, would this be tolerated by patients, the public, healthcare providers or politicians? The same rule applies for treatment duration, which is frequently determined by service configuration.

Patients are frequently offered one course of treatment that consists of a specified number of sessions. Patients frequently cannot access therapy for more than a limited number of sessions (even if they have not recovered) neither can they be offered more than one course of treatment. Putting this into the context of physical health problems again, it is equivalent to providing cancer patients with only one round of chemotherapy irrespective of its outcome (whether the cancer has been cured or not). Long waiting times is another barrier to individuals accessing services, which has a negative impact on peoples' mental health⁵⁵, as well as effectiveness of therapy (once offered)⁵⁶. GPs often resort to prescribing medication to patients, "as the waiting times for talking therapies are too long and they want to keep their patients safe"⁵⁷. The prescription of anti-depressant medication has been steadily rising in England³⁴. This may be due to the better identification and treatment, rising prevalence of depression, insufficient access to psychological treatments or unwarranted variation in prescribing behaviour³⁴. Some scholars have attributed the increase of these interventions to new medications (particularly those based on Selective Serotonin Re-uptake Inhibitors or SSRIs) due to their favourable side-effects and the ease of providing a therapeutic dosage, compared to tri-cyclic anti-depressants²⁶. Medications work on the molecular level and aim to alter the balance of neuro-transmitters in the brain deemed responsible for the emotional state of the individual. Many patients, however, do not adhere to their treatment regimens for a variety of reasons, such as the dependency effects of such medicines and/or their ineffectiveness in ameliorating/treating the patients' emotional distress²⁶. As such, health professionals need to plan, negotiate, and agree with patients their care needs,

for example, by practising 'shared-decision making' with patients⁵⁸, that is, considering patients' individual needs, which at times, may be at odds with evidence-based practice for mental health problems⁵⁹. Like other studies^{11 44}, participants reported mixed views on using prescribed medication; whereas some participants considered them as a component of self-care, other participants did not, and talked about their negative effects on their mental health.

In England, community mental health care services are centred on diagnosis and organised around a stepped care model where, at the lowest level, the clinician is the primary tool of intervention (i.e. watchful waiting), and at its highest (where risk for the individual or other people is involved), treatment is based upon the use of pharmacological interventions and combinations of therapy, such as CBT and medication^{58 60}. The basic premise of the stepped care approach in the treatment of CMHP is that patients will improve when they receive the treatment at a certain step, and therefore, the less intrusive form of treatment will benefit both the patient (i.e. the patient is not exposed to unnecessary courses of treatment) and the system (i.e. costs). This system enhances the efficiency and effectiveness of a service; for example, resources are distributed to maximise health gains and services improve health^{59 61}.

However, our findings show that participants rarely had a choice⁷ over their treatment option, with psychotropic medication being the first intervention to be offered. Previous research has shown that when patients have choice over their treatment, then they are more likely to engage with services, and adhere to rather than drop-out from treatment⁵⁶.

⁷ Currently, commissioners and providers are not required to deliver the full range of NICE recommended therapies in IAPT (e.g. interpersonal therapy, behavioural activation, counselling, psychodynamic psychotherapy).

Problematic interactions with healthcare professionals also negatively affected participants' willingness to access care, ability to practice self-care. Participants reported that often GPs were inadequately trained and skilled in providing support to patients with mental health problems. Many participants described themselves as 'lucky' for having managed to find a GP who listens to them, shows empathy towards their mental health concerns, and is willing to make onward referrals to mental health services. Governmental policies and clinician membership organisations have highlighted the need for better mental health training at all levels of the healthcare system; similarly, the Chief Medical Officer has stated: "There should be a period of specific mental health training in GP training⁵⁶. Mental health needs should be included as a core module in the curricula of medical practitioners and social care professionals, and be part of their continuous professional development. Similarly, owing to the high number of people with long-term health conditions and co-morbid mental health problems, psychological therapists need to receive some basic training in physical healthcare⁵⁶.

8.1. NOVEL FINDINGS

Some of the findings discussed have not previously been reported in self-care research. These novel findings can be described as the new knowledge that this particular

research project has generated, and therefore, contribute to the wider literature on self-care in mental health. These findings are primarily centred around the ways in which contextual factors (e.g. social and physical health problems) influence peoples' ability and motivation to engage and practice self-care.

Participants reported that, even though they wanted to practice self-care, social (e.g. financial problems and loneliness) and physical health problems influenced their ability to do this. For instance, some participants said financial difficulties prevented them from undertaking activities that could have a positive impact on their mental health, like exercising in a gym. As a result, participants had to either stop exercising or find other ways to achieve their aim (e.g. buy equipment and exercise in their homes). However, these alternatives often appeared to be counterproductive because they encouraged participants to stay indoors rather than interact with people outside of their own four walls. Other participants talked about how physical health problems and disabilities affected their ability to do outdoor activities such as going for walks.

Many participants also talked about how such problems not only affected their ability to practice self-care, but also had a negative impact on their mental health.

9.0

The importance of in-depth narrative data



Compared to research studies that have exclusively relied upon surveys to examine peoples' views on self-care in mental health, this study, by employing the method of group discussion, has generated deeper insights into peoples' lived experience of mental health, views of self-care and experiences of healthcare professionals and services. This focus helped us explore the meanings that people attach to these social phenomena as well as their views on how primary care services could better support them in practicing self-care.

10.0

How do our findings relate to English mental health care policy?

Across the group discussions participants highlighted some issues that underlie and cut across English mental health care policy, such as personalised care, parity of esteem between physical and mental health, and the risk-based criteria around which several mental health care services are configured in England.

Mental health policy in England is centred on the recognition that good general health requires good mental health and the development of personalised services⁶³⁶⁴. The green paper *“No Health Without Mental Health”*⁶⁵ and *“The Five Year Forward View for Mental Health”*⁶⁶ set out the new mental health outcome strategy. These strategies acknowledge the role of mental health in improving the overall health and prosperity of the nation and calls for a parity of esteem between physical and mental health. They also recognise the importance of care services to improve quality, delivery, and organisation of mental health care services. Mental health policy initiatives have increasingly focused on personalisation via an emphasis on addressing the wider needs of people with mental health problems, such as addressing inequalities and tackling social exclusion⁶³⁶⁴. The trend towards more personalised services has also been guided by an increasing awareness of peoples’ different experiences of health care, according to race, culture, and ethnicity⁶⁷. For instance, studies have shown that mental health care services have failed to provide adequate and good quality care to patients from black and ethnic minority groups or other socially excluded groups, such as offenders and older adults⁶⁸⁶⁹.

The minimisation and management of risk is another factor that has partially driven mental health policy in England⁶⁶⁶⁹. This emphasis on risk has been attributed to how, in the 1990s, the media and politicians exploited a small number of homicides committed by people with personality disorders, and hence, an impression emerged that mental illness is inextricably linked to dangerousness⁶⁹⁷⁰.

Although the trend in mental health policy and wider scholarship is that care should be holistic and person-centred⁶⁰⁶¹⁶⁶⁷¹ (a trend that participants also supported) the reality for both service users and professionals is that mental health care is under-resourced, fragmented and based upon diagnosis⁶⁶⁶⁹. Firstly, it appears that there is an inequality within the NHS between the ways it treats physical compared to mental illness⁸. Although the scale, severity, and overall cost of mental illness to the person and wider society are far greater than those of physical illness, funding is unfairly distributed between physical and mental health services⁷²⁷³. For instance, it has been reported that mental illness accounts for nearly 40% of morbidity, compared with, for example, 4% due to digestive diseases or 2% due to diabetes⁷². Although mental health problems account for 23% of the total burden of disease, mental healthcare accounts for only 13% of NHS expenditure. Secondly, there is strong evidence of the impact of poor mental health on physical health and vice versa⁷³; nonetheless, services have failed to create partnerships and strengthen the interface between different care domains (i.e. physical/ mental health care, health/social care, primary/ secondary care)⁷³.

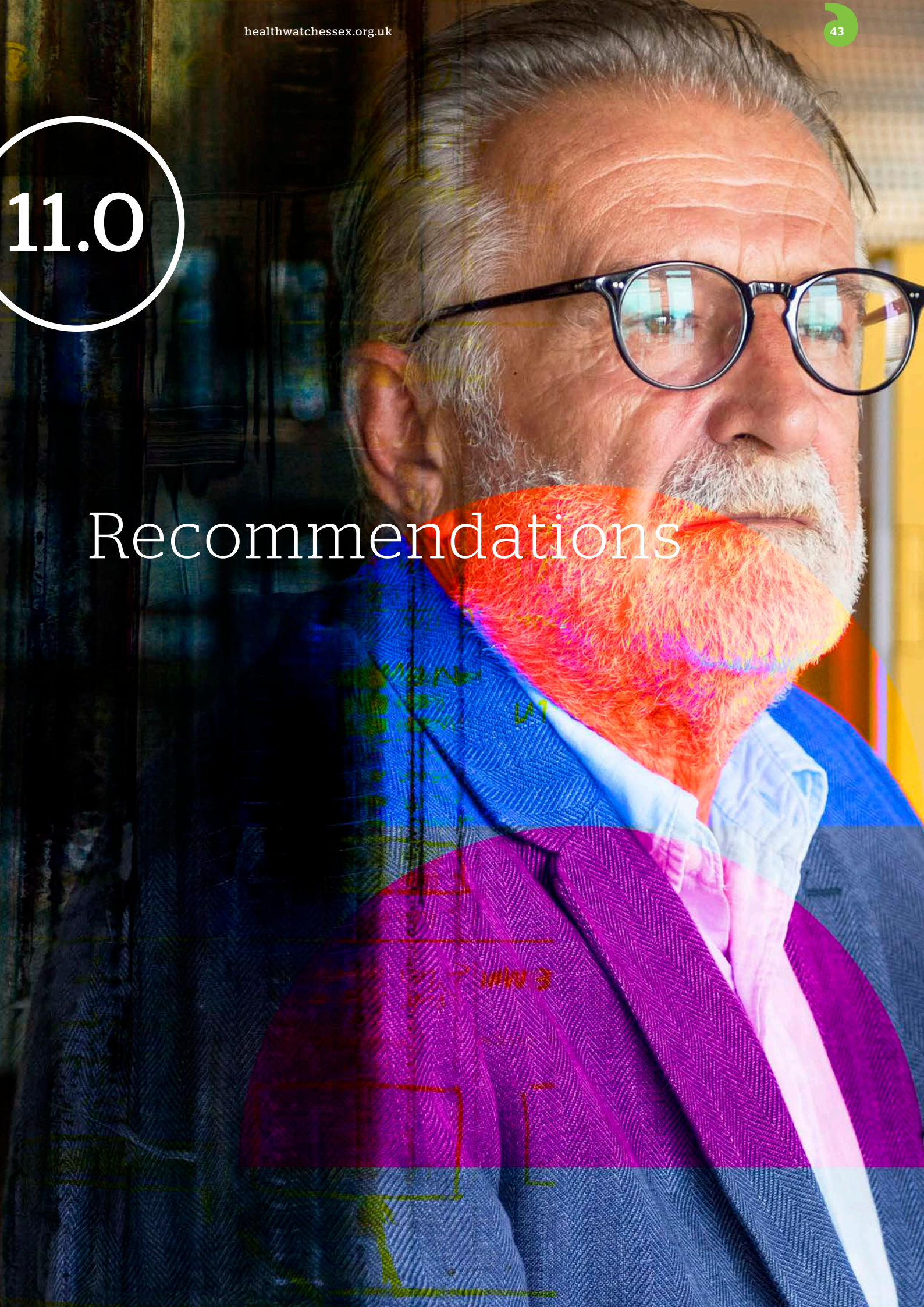
⁸ Although the NHS budget is ring-fenced, the same rule does not apply to local authorities, which provide substantial financial and social support to people with mental health problems, but have had their budgets significantly reduced.

The lack of service integration allows people to fall through gaps in care and, hence, has a negative impact on people's experience of continuity of care⁷³. Thirdly, despite the prevailing trend in research outputs and mental health policy, which favour the provision of holistic and person-centred care, NICE guidance continues to emphasise diagnosis and symptom change, which marginalises the impact of life stressors on mental health⁷⁴. This is particularly important

as peoples' mental health is often affected by and in turn can exacerbate poverty, trauma, and housing problems⁷⁵. By leaving unaddressed the problems and experiences that have negatively influenced peoples' mental health, service provision risks widening health inequalities, thus preventing them from accessing and receiving much needed help and increasing the cost of mental health care (i.e. A&E visits).

11.0

Recommendations



Our findings support the widespread and accepted view that primary care mental health services (can) play an important role in the treatment and care of people with CMHPs, such as anxiety and depression.

Our findings also provide evidence about the appropriateness of such services to strategically focus on supporting people to practice self-care in mental health⁷⁶. Within this context, we believe that local service providers and commissioners should aim to be developing services that not only target symptoms and diagnoses; they should also help people maintain positive mental health, which can contribute to an improved quality of life. Such services should help people address a variety of issues, such as unemployment, housing problems, loneliness, and physical health problems, that have negative effects on their ability to self-care and contribute to poor mental health.

Our participants reported a variety of issues that cut across different levels of the healthcare system, such as healthcare professionals, services providers, and commissioners. The following recommendations aim to inform GPs and local clinical commissioners and service providers about how primary care mental health services could be improved. The recommendations presented below should not be considered definitive or comprehensive, but they are a start. Therefore, Healthwatch Essex welcomes comments, constructive feedback and suggestions relating to the recommendations presented below.

11.1. RECOMMENDATIONS FOR GPs INTERACTING WITH PEOPLE EXPERIENCING ANXIETY AND/OR DEPRESSION

- 1.** Do not just look for symptoms; look also for stories and explore how these stories contribute either positively or negatively to peoples' emotions, thinking, social situation, and identity. Explore how your patients understand self-care and which activities they believe can contribute towards improving and/or maintaining positive mental health.
- 2.** You are already part of your patients' self-care routine if, during your encounters, you use your everyday human skills of empathy, active listening, and a non-judgemental stance towards them. It is important to make them feel that their mental health concerns are listened to and acknowledged. Such practices can make your patient feel valued, which can motivate them to practice self-care.
- 3.** Avoid making any assumptions; instead show an interest and ask your patient how they view their problems or the reasons they believe they experience emotional distress. Be patient and give them time to express themselves. Use open ended questions and expressions that will permit your patient to talk about themselves. This will allow rapport and trust to develop between you. Make sure that your patient is comfortable discussing these issues.
- 4.** Work with the patient and not on the patient; create partnerships and share decision-making. Your patient is very likely to welcome your support and advice on how to practice self-care. Explore what is important for them and what they need. Identify issues that may affect their ability to practice self-care, such as social and physical health problems. Provide consistent support by scheduling regular follow-up meetings, even during times when the patient is (or appears to be) doing well, to provide reassurance and support to your patient.

5. Get familiar with the mental health care services offered in your locality; establish systems that will enable you to get updates about the range and availability of such services.

11.2. RECOMMENDATIONS FOR SERVICE PROVIDERS AND COMMISSIONERS

1. Service users consider seeking and receiving professional support to be an integral aspect of practicing self-care. Create simple and easy to understand pathways for people to access mental health services. Set up and/or promote awareness campaigns about the mental health services that you deliver in your locality and provide clear and concise information about how people can access them.

2. All healthcare staff across the healthcare system (e.g. primary and secondary care) who are likely to interact with people who experience mental health difficulties should receive mandatory training in mental health. Such training would aim at improving staffs' communication skills and ability to respond with compassion when they interact with an individual who experiences emotional distress.

3. Focus on prevention by developing educational programmes that will help people to learn how to acknowledge and accept their emotions; design and offer activities that can assist people with practicing self-care in mental health.

4. Offer to service users the opportunity to choose their own care; personalised mental health care budgets might present an opportunity for service users to decide what treatment modality or activity can better address their mental health needs (e.g. going to the gym, attending yoga classes).

5. Consider developing a service equipped with trained staff capable of providing mental health care and support 24/7. Such service will support people who cannot access a GP (e.g. during weekends/evenings), and are not suicidal or at risk so would not be likely to contact Samaritans or be accepted by Accident and Emergency services.

6. Support and encourage the development of peer support groups in your locality (or GP practice); such groups allow patients to interact with people experiencing similar mental health problems, share their experiences and help each other. Consider the possibility of employing experts by experience to train GPs in providing mental healthcare.

7. Individual recovery should determine the length of therapy as opposed to pre-determined time-limited therapy; many participants felt that the support they had received was insufficient to address their mental health needs.

8. Aim to provide a wider choice of evidence-based psychological interventions to patients; patients should receive high quality information about the range of evidence-based therapies available. If service users' preferred therapy is not offered locally, provide information about where the preferred therapy is provided and how they can access it.

9. Set up explicit targets from referral to assessment to treatment; ensure that patients receive treatment within 28 days of referral and assessment (as per national guidance).

12.0

What's next?

Our findings demonstrate that people require holistic and consistent support from primary care mental health services; such support contributes towards their ability and motivation to engage with and practice self-care, and thus, can contribute towards improving their mental health. The following questions may help health and social care commissioners and service managers to start reflecting about self-care in mental health and its position within their local health economies:

- 1.** Do the local authority and clinical commissioning groups have a self-care strategy in mental health?
- 2.** What range and type of self-care support is available and for whom is it provided within CCGs and local authority?
- 3.** Are there any self-care support activities happening within the CCGs and local authority, and if yes, are they contained within an overall strategy and labelled as such?

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