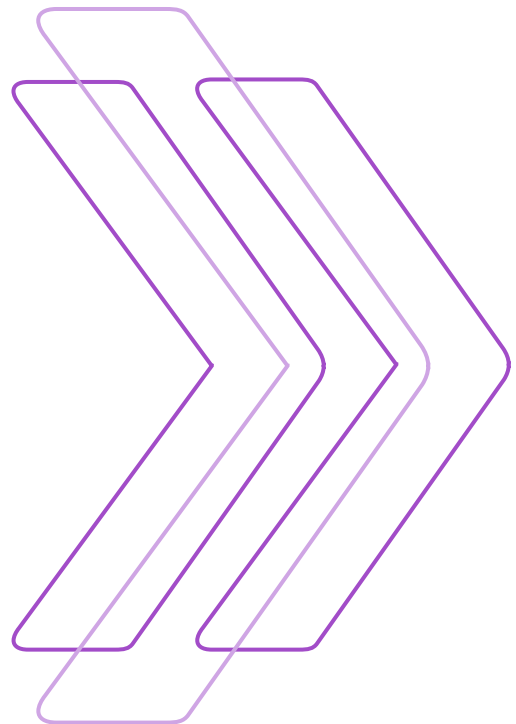# Outcomes for mental health services

What really matters?

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This independent report was commissioned by Janssen. The views in the report are those of the author and all conclusions are the author's own.

The King's Fund is an independent charity working to improve health and care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible health and care is available to all.

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1 Introduction

In June 2006, the economist Michael Porter and the strategist Elizabeth Teisberg published their ground-breaking work, *Redefining health care*, on how to improve the performance of modern health systems (Porter and Teisberg 2006). According to their analysis, health care providers in the United States and other countries focused on delivering as many procedures as possible, with little concern for the costs of care or what benefits they were achieving for patients. The solution was to reward providers not for activity, but for how well they delivered a full cycle of care for groups of patients based on clear outcome measures: for example, how many patients receiving surgery for lower back pain suffered complications, required a further operation, continued to rely on pain medication, or were able to return to work? In short, health systems needed to refocus from activity to value, with value defined as health outcomes divided by the cost of delivering them.

While the initial focus was on improving value in physical health services, attention has turned to achieving value in services for people with mental health problems. In England, there are legitimate reasons to inquire into how mental health services use their resources and the benefits they achieve for service users and communities. Every year, large numbers of people with more severe mental health problems still enter 'locked rehabilitation' wards – often for long periods, too often far from home, with highly variable rates of actual rehabilitation or recovery (NHS Digital 2018; Wright 2017). Some services for people with mental health challenges have been accused of 'warehousing' or 'containment' rather than helping people live more fulfilling lives (Cottam 2018; Independent Review of the Mental Health Act 1983 2018). Meanwhile, Lord Carter's review of productivity in mental health and community services called for the collection of better-quality data on activity, cost and outcomes in order to assess performance (Lord Carter of Coles 2018).

For proponents of value-based health care, there is a simple remedy for these concerns. As for physical health, purchasers need to define more clearly the desired outcomes from particular groups of mental health services and hold providers more rigorously to account for delivering them – for example, adherence to good clinical practice and measures of improvement in health and wellbeing. Over recent decades, a wide range of measures and frameworks have been developed, including questionnaires to assess the severity of particular mental health conditions such as anxiety or depression, and frameworks to assess broader aspects of people's lives. For many professionals, the priority now is to accelerate this work, setting and applying the types of precise performance measures for mental health that have delivered improvements in the treatment of some physical health conditions – perhaps the equivalents of measuring haemoglobin A1c levels for people with diabetes or ensuring the prescription of statins for people with cardiovascular disease.

Even the briefest discussion with service users shatters the illusion that agreeing these outcomes will be an innocuous administrative exercise. During our research for this paper, we spoke to more than 100 people actively involved in mental health services in England, including current and former service users, peer support workers with lived experience of mental health challenges, staff in clinical commissioning groups (CCGs), clinical staff in NHS services, and staff in voluntary sector services (*see* appendix). While there are many strong partnerships between service users and NHS services, there was also evidence of profound differences in perspective on what is important and even, at times, outright hostility and distrust between the two sides.

Some service users are suspicious of the value and motives of health services which, as they see it, treat narrow clinical aspects of mental illness, such as controlling the medical symptoms of a disorder, in ways that damage people's sense of empowerment and self-esteem (Wade and Halligan 2017; Deacon 2013). There is disquiet at the use of oppressive interventions on mental health wards: rapid tranquilisation, face-down restraint or prolonged seclusion

(McVeigh 2017; Sacks-Jones 2017). There is concern about how people can be traumatised in a broader set of services: for example, accident and emergency (A&E) departments or police stations (Independent Office for Police Conduct 2018; Royal College of Nursing 2017). Some people with mental health problems prefer to seek help from organisations that operate as an alternative and, in some cases, an opposition movement to traditional health services (Beresford 2016); Lawton-Smith 2013).

For sincere NHS professionals, these blunt accusations are hard to bear. Anyone who has tried to support a friend or family member with mental health problems knows how difficult it can be to make a useful contribution. Staff in NHS services are exhausted too; they have no immunity to accumulated demoralisation when they see the same patients in their clinics, caught up in the same cycles, struggling to make progress. Across the NHS, staff are attempting to deliver good services to a growing number of people with mental health problems in a context of severely constrained resources.

At the same time, people with mental health problems are among the 'problem patients' of modern health care – those that seem to rub the system up the wrong way and wear professionals down with their stubborn refusal to be cured (Kleinman 1989). Professionals betray their frustrations in the language they use to describe patients: 'difficult', 'manipulative', 'non-compliant' (Roe and Davidson 2017; Knaak *et al* 2015). While many clinicians recognise service users' complaints, there is a tendency to downplay the extent of their dissatisfaction (Crichton *et al* 2017). Meanwhile, there is some suspicion of radical alternatives to traditional NHS services. As one clinician put it, 'We don't practice quack medicine here'.

Whatever credence you give these perspectives, this is clearly not a discussion about minor details, about the fine-tuning of the system. It is a disagreement on issues of fundamental importance: our understanding of the concept of mental illness; the role of health care in addressing it; the acceptability of particular ways of treating people; the relative importance of different time-honoured goals of medicine – alleviating pain or doing no harm,

for instance. If I am rushed into hospital with trauma after a car accident, I and those caring for me are likely to have a reasonably clear shared sense of priorities. In the care of people with mental health conditions, and perhaps people with other chronic conditions, there is a much broader range of sometimes contested objectives. In such a maelstrom, an exercise to define outcomes could never be an anodyne process, even if it is sometimes treated as one. The outcomes prioritised, and those discounted, inevitably reveal the degree of influence of different voices in the discussion – those around the table and those outside the room.

This paper considers various approaches that have been adopted in the design and pursuit of high-level 'outcomes of care' for mental health services. These outcomes of care might include reductions in the medical signs and symptoms of illness, improvements in functioning, life expectancy, the development of capabilities needed to live a fulfilling life, or improvements against measures of the quality of people's lives. The paper considers the approaches that some commissioners have adopted to specifying desired high-level outcomes of care in their contracts for services. It also includes the approaches that health care providers have adopted to defining and measuring high-level outcomes of care. It reflects on the advantages and disadvantages of current approaches, all of which have their merits, and makes some suggestions for the future.

One thing is certain in this debate: we cannot usefully direct mental health services to the dogged pursuit of particular outcomes until there is a broader consensus on which outcomes really matter. Where service users, professionals and different professions already appear to be pulling in different directions – each blaming the other for their dissatisfaction with the current system – that kind of approach would simply create further antagonism. It is also clear that some sort of reconciliation is urgently needed. Unfortunately, any serious reflection on desired outcomes from mental health services quickly leads us away from unthreatening technical discussions to much bigger questions about the purposes of health and care services. These are harder questions than we signed up to when we started

the project! Nevertheless, we must collectively try to address them, so that public services can use public resources in ways that have public legitimacy, and so that people understand what they can reasonably expect of health care.

2 Health outcomes

If you ask clinicians in NHS mental health services how they measure outcomes, they are most likely to refer to one of the large number of clinical scales that have been developed since the early 1990s to assess whether patients have particular mental health conditions and, if so, the severity of their conditions. In the mid-1990s, researchers at Columbia University developed the nine-item patient health questionnaire (PHQ-9) to assess depression and the seven-item generalised anxiety disorder (GAD-7) scale to assess generalised anxiety disorder (Spitzer *et al* 2006; Kroenke *et al* 2001). In the same period, the Royal College of Psychiatrists developed the Health of the Nation Outcome Scales (HoNOS) to measure the health and social functioning of people with more severe mental illness (Wing *et al* 1998).

At least to the lay person, these assessment tools appear to operate in much the same way. There is a series of questions about how patients are feeling or functioning. For example, the GAD-7 questionnaire on anxiety asks: how often over the past two weeks have you been feeling nervous, anxious or on edge; how often have you been worrying too much about different things; how often have you had trouble relaxing, and so on (Figure 1). Meanwhile HoNOS captures the extent of behavioural problems, self-injury, drinking, drug-taking, hallucinations and delusions, and depression, among other things. Once the patient or clinician has completed the questionnaire, staff calculate an overall assessment score based on the responses.

It is interesting to note that there is usually no particular set or pattern of responses that indicates a disorder. Instead, patients with a score of 0–4 on GAD-7 are deemed not to have anxiety; those with a score of 5–9 are deemed to have mild anxiety; those scoring 10–14 are deemed to have moderate anxiety, and so on. Like the traditional diagnosis of chronic obstructive pulmonary disease (COPD), patients who score sufficiently highly based on various tests are deemed to have the condition, but the underlying

nature and causes of the condition can vary considerably between patients and remain unclear.

In the NHS, clinicians and managers use the scores from GAD-7, PHQ-9, HoNOS and other questionnaires for a variety of purposes: to make a tentative diagnosis; to make an assessment of severity; to aid decisions such as whether to refer to another service; to guide therapy sessions; and to monitor how people's conditions change over time. In the Improving Access to Psychological Therapies (IAPT) programme in the NHS, GAD-7 and PHQ-9 scores are used both as a tool to assess and monitor patients, and to performance-manage services, with payments linked to improvements in patients' questionnaire scores over the course of their therapy.

Clinicians and researchers have highlighted the potential benefits of using these types of questionnaires as part of routine clinical care. For example, clinicians have reported that using severity questionnaires has given them confidence in treating mental health problems (Tavabie and Tavabie 2009). There is some evidence that they support decision-making on when to treat people in primary care and when to refer to secondary care (Mathai *et al* 2002). According to some research, patients can interpret the use of questionnaires as evidence that clinicians are taking their problems seriously and making a thorough assessment (Dowrick *et al* 2009).

Dr Michael Smith, Associate Medical Director at NHS Greater Glasgow and Clyde, highlighted the benefits for performance improvement:

> *When I started working, we measured everything – waiting times, number of contacts, duration of treatment – except the actual outcomes of care. But activity data has limited value unless you can link it to outcomes. We could say how many people had received services, but not which teams or services were better. Suddenly, we had lots of rich data on outcomes from services*.

Other researchers have used this type of data to highlight substantial variation in the effectiveness of different teams (Okiishi *et al* 2003).

At the same time, interviewees were conscious that these traditional assessment frameworks need to be used with care. One particular concern is that they focus attention on clinical issues and away from other important matters. For Nigel Henderson, Chief Executive of the mental health charity, Penumbra, these frameworks concern themselves with the clinical assessment of mental health disorders while ignoring the nature of people's lives. They focus almost exclusively on measuring and controlling the signs and symptoms of illness, with at best only a brief glance at the broader social issues (such as employment or housing) that may contribute to ill health.

Service users and staff in voluntary sector organisations emphasised the tendency of clinical services to recast the complexities of people's lives, and the vast array of influences that underlie mental illness, in the narrow terms of a medical disorder. Where anxiety is reframed as a thyroid disorder, confirmed by a thyroid function test, leading to a course of Levothyroxine, this simplification might be an enormous success. Where a diagnosis of depression leads to a prescription of selective serotonin reuptake inhibitors to control the symptoms, but where the family breakdown, workplace conflict and financial crisis go unnoticed and unaddressed, the same reductionism seems likely to lead to frustration and failure (Walker 2016; Beresford 2002; Engel 1977).

The physician Eric Cassell has described how, from the mid-twentieth century, cardiologists were able to use echocardiograms and other new technologies to assess the functioning of the heart organ. Cardiologists refocused their attention away from the patient to the tests, the technology and study of the functioning of the heart in isolation, just as heart disease was itself starting to be understood as a complex, individual lifestyle disorder (Cassell 2004).

It is surely worth considering whether the measurement of clinical outcomes in mental health can also come between the clinician and the patient, preventing the clinician from seeing the whole person and undermining the

quality of their relationship. It is possible to envisage clinicians using these frameworks skilfully as a basis for a thorough discussion with their patients. It is equally possible to envisage the measurement of outcomes degenerating into a box-ticking exercise, one that focuses attention on the thinned-out generalisations of the questionnaire scores and away from more productive forms of therapy. (Others have raised similar concerns, including: Leydon *et al* 2011; Mitchell *et al* 2011; Gubb 2009; Happell 2008.)

Michael Smith told us that staff in his depression clinic in Glasgow had started to talk about 'the thing with no name, this strange ingredient X, which I think really reflected engagement and connection between clinician and patient'. They concluded that at least one component of this ingredient was simply curiosity: profound and sincere curiosity about the person on the other side of the table based on a sense of human connection and engagement. For Michael, 'It's one of the reasons why I have become more suspicious of traditional outcomes frameworks – they just can't capture these two critical therapeutic factors of curiosity and connection'.

For service users, it can be deeply disempowering when clinicians discount their understanding of their own illness, stripping their experience back to a set of symptoms and converting individual suffering into a 1–10 score in the search for a diagnosis. Young people we spoke to at Off the Record, a charity in Bristol, resented the implication that their mental health problems were entirely in their own minds, as opposed to a product (at least in part) of how society is organised. As Charlotte Randomly, a team leader at Off the Record, explained: the prejudice, brutal schools system and lack of opportunity causing ill health in young people is discretely put aside; instead, young people are given a medical diagnosis, some pills and advice on coping strategies. For some activists, services that reframe complex problems as health issues are, intentionally or not, participating in a political agenda, reframing society's injustices as personal problems so that society can ignore them.

Figure 1 Generalized anxiety disorder (GAD-7) questionnaire

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1 Feeling nervous, anxious or on edge	0	1	2	3
2 Not being able to stop or control worrying	0	1	2	3
3 Worrying too much about different things	0	1	2	3
4 Trouble relaxing	0	1	2	3
5 Being so restless that it is hard to sit still	0	1	2	3
6 Becoming easily annoyed or irritable	0	1	2	3
7 Feeling afraid as if something awful might happen	0	1	2	3

Total score ____ = Add columns __ + __ + __

If you checked of any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all   Somewhat difficult   Very difficult   Extremely difficult
☐   ☐   ☐   ☐

Source: Spitzer *et al* 2006

3 Developing capabilities

For the recovery movement that developed from the early 1990s, a key objection to traditional biomedical approaches in mental health was precisely the focus on managing medical symptoms, rather than addressing the underlying causes of people's mental health conditions. While large numbers of people were still being locked up in asylums, a series of World Health Organization studies from the 1970s had shown that significant numbers of people could recover from even serious mental illness (Sartorius *et al* 1974). But this clearly required a different approach to that on offer in developed countries' traditional mental health services.

Nigel Henderson, at Penumbra, an active member of the Scottish recovery movement, described how these ideas changed the organisation's approach both to the support it offered people and how it defined and measured outcomes.

> *We started asking what difference we were really making to people's lives. We had always maintained that we were a person-centred organisation, that we focused on the needs of the person rather than the delivery system. But the only evidence we could find that we were actually doing this was anecdote.*

In the mid-2000s, staff at Penumbra developed a new framework, with the acronym HOPE, for helping people with mental health challenges to recover: home (having a safe and secure place to live); opportunity (pursuing meaningful leisure, recreation, education and work); people (having friends, confidantes and supporters); and empowerment (being fully involved in decisions affecting one's life). At the same time, they developed a measurement tool, the individualised recovery outcomes counter (I-ROC), with 12 indicators on a 6-point scale, to measure people's levels of wellbeing

over time: at the start, during a support programme, and at the end of the programme.

Many similar frameworks have now been developed. In 2008, the Association of Mental Health Providers, with Triangle Consulting, developed the recovery star, which measures resilience in 10 areas of people's lives, including managing mental and physical health, living skills, relationships, work, identity and self-esteem (Figure 2). In the late 2000s, the social entrepreneur Hilary Cottam (2018) developed a framework and tools for measuring four capabilities needed for a good life: the ability to create and sustain social relationships; the ability to work and learn; the ability to manage one's health and vitality; and the ability to actively care for and contribute to the community. These frameworks appear to be used widely in non-medical mental health services – in particular, voluntary sector services and, to a smaller but growing degree, in clinical services.

Figure 2 The Recovery Star ™
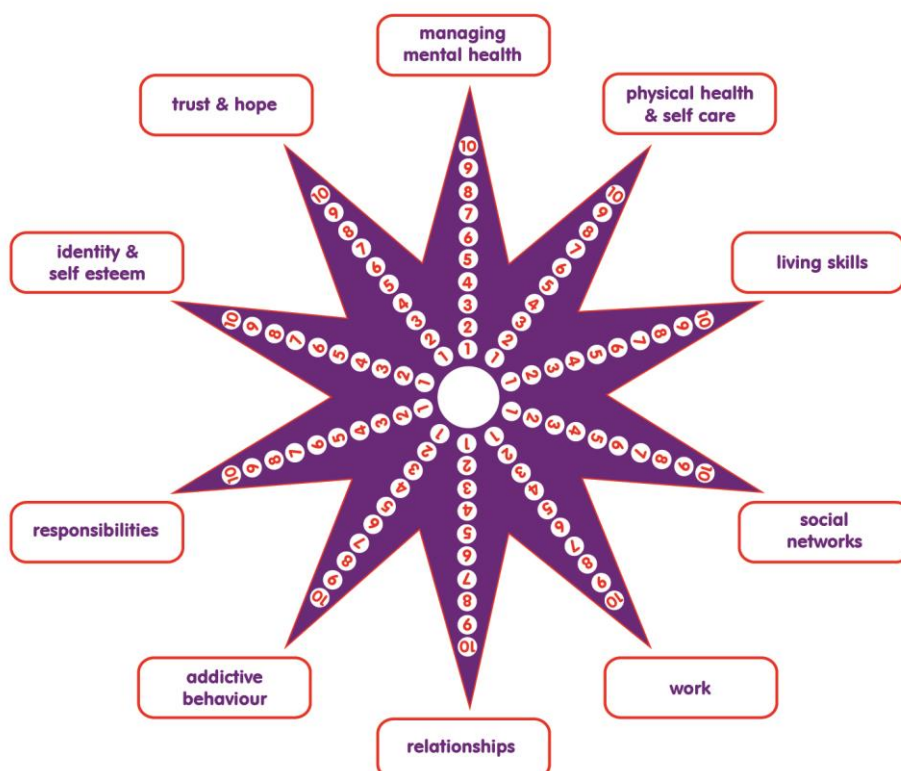
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In 2013, Oxfordshire CCG ran a series of engagement exercises with service users and carers to understand what they really wanted from services. Juliette Long, the CCG's senior commissioning manager for mental health, explained:

> *What service users and carers were saying was not surprising. They wanted better care of their physical health, settled accommodation, to get into employment. But from a contracting point of view, this was miles away from what we were doing. The outcomes people cared about were radically different to the normal, activity-focused indicators for NHS mental health services.*

Three years later, the CCG entered a new five-year contract with a partnership of Oxford Health NHS Foundation Trust and five voluntary sector organisations to deliver integrated mental health services. The partnership's priorities are ensuring that people live longer, that they improve their level of functioning, that they suffer fewer physical health problems, that they live in stable accommodation, and that they maintain a role that is meaningful to them.

Leaders of the partnership explained how they were working together to deliver these outcomes. Across services, there is a greater focus on people's physical health, rather than just their mental health, ensuring that they receive proper support to manage chronic physical health conditions and make lifestyle changes that will improve both physical and mental wellbeing. The King's Fund has argued separately for the need to move beyond the concept of parity of esteem between physical and mental health to integration of support for physical and mental health (Naylor *et al* 2017).

The services in the Oxfordshire partnership are also working much more closely together to co-ordinate the different forms of support people need to leave hospital. Large numbers of people lose their tenancies when they enter inpatient mental health services. If you have damaged your flat or not paid your rent, a hospital stay is an excellent opportunity for your landlord to evict you. As soon as people enter an inpatient ward, the Oxfordshire partners are

working together to put in place the housing, benefits advice, and health and social support they will need when they move back into the community.

Another potential benefit is the gradual shift from a medical model to a more holistic, social model for supporting people with mental health challenges, with medical care as a component for many people but not necessarily the most important part. John McLaughlin, Chief Executive of Response, a charity providing housing in Oxfordshire, described the effect of work placements at Response's partner RAW (a social enterprise that offers training in its woodworking workshop):

> *You see young people coming in, hunched over, run down, looking at the floor. A couple of weeks later their shoulders are back, their heads are up, they've got a work uniform on, they feel part of something, and it changes the whole way they think about themselves.*

Despite these significant benefits, not everyone is happy with all aspects of the model. In Oxfordshire, the commissioner has gone further than in other areas to link payments to high-level outcomes, with no less than 20 per cent of the budget payable depending on the partnership's performance. Stuart Bell, Chief Executive of Oxford Health NHS Foundation Trust, emphasised the difficulties of measuring high-level outcomes such as changes in life expectancy. He also expressed concern that a focus on outcomes could lead to transactional care: 'There is a real risk that we start telling service users that this is the outcome you need to have because this is the outcome in the contract.'

Staff working directly with service users in Oxfordshire shared these concerns. They described their frustration at having to counsel people on smoking cessation and, as they put it, 'nag them' about weight loss, with the humiliating ritual of putting people on a set of scales to calculate their body mass index, simply because doing so was incentivised in the contract. Many of their patients were grappling with rather more immediate challenges. Some

were on anti-psychotics that can make weight loss extremely difficult; stopping smoking at the same time would just make weight loss even harder.

Service users, clinicians, voluntary organisations and academics have also raised concern that the narrow pursuit of generalised outcomes for health and wellbeing within recovery models will distract from the needs of the individual and lead to mechanistic, 'cookie-cutter' approaches to care. The clinical psychologist Jay Watts raises the possibility that recovery models are used to pressurise people with mental health problems to behave in particular ways (Watts 2016). The academic Diana Rose argues that recovery models encourage service users to focus on 'permitted' personal goals, while excluding others (Rose 2014). The activist collective, Recovery in the Bin, argues that recovery frameworks can represent 'a narrow and judgemental view of wellness'. Meanwhile, researchers have highlighted divergence between the outcomes that service users care about and those focused on within recovery models, with service users suspicious of some measures of improvement in functioning or social networks (Crawford *et al* 2011).

Staff and service users at Off the Record expressed concern about the measurement of recovery outcomes through their ironic recasting of the recovery star into a 'recovery "octopus"'. Service users define what outcomes matter to them and colour in parts of the octopus's tentacles rather than calculating scores (*see* Figure 3). Meanwhile, the Recovery in the Bin collective has developed the 'unrecovery star', a framework that focuses on the social and economic factors causing mental health problems, challenging the belief that the solutions for people with mental health problems lie within the person rather than broader social change (*see* Figure 4).

One criticism of the recovery model, as it has been applied in public services, is that it assumes that people should pursue a common end goal of complete recovery from mental illness. Under the model, services are structured to avoid creating dependency and to return people quickly to their communities. Yet, while many people can recover from even severe mental illness, there are surely groups of people who are unlikely to do so, where the objective of

recovery is potentially a dangerous misconception. As Ellie Walsh, Assistant Director of Acute Mental Health Services at NAViGO (a social enterprise that delivers health and care services for people with mental health challenges in Grimsby) explained:

> *Many people who visit our acute services will recover and go on to live entirely independent lives. But a few will struggle to develop the skills and networks. If we have to sit some people under our umbrella and support them for the rest of their lives, why on earth wouldn't we do that?*

Figure 3 The recovery octopus
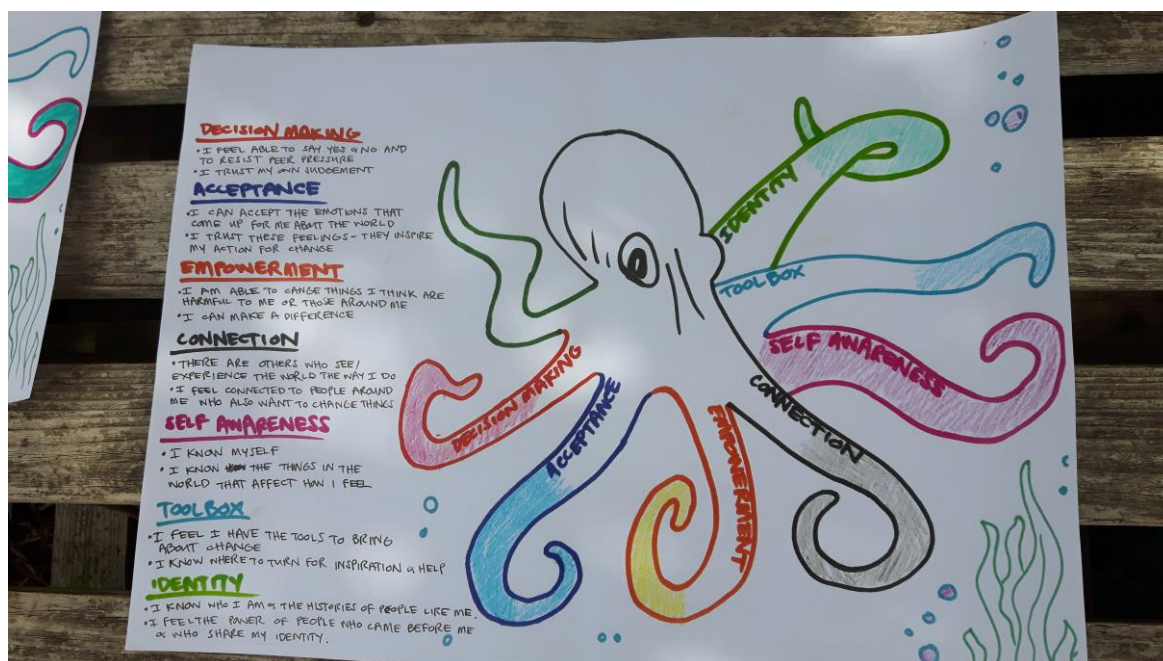
Source: Off The Record Bristol – www.otrbristol.org.uk

Figure 4 Recovery in the Bin's 'unrecovery star'
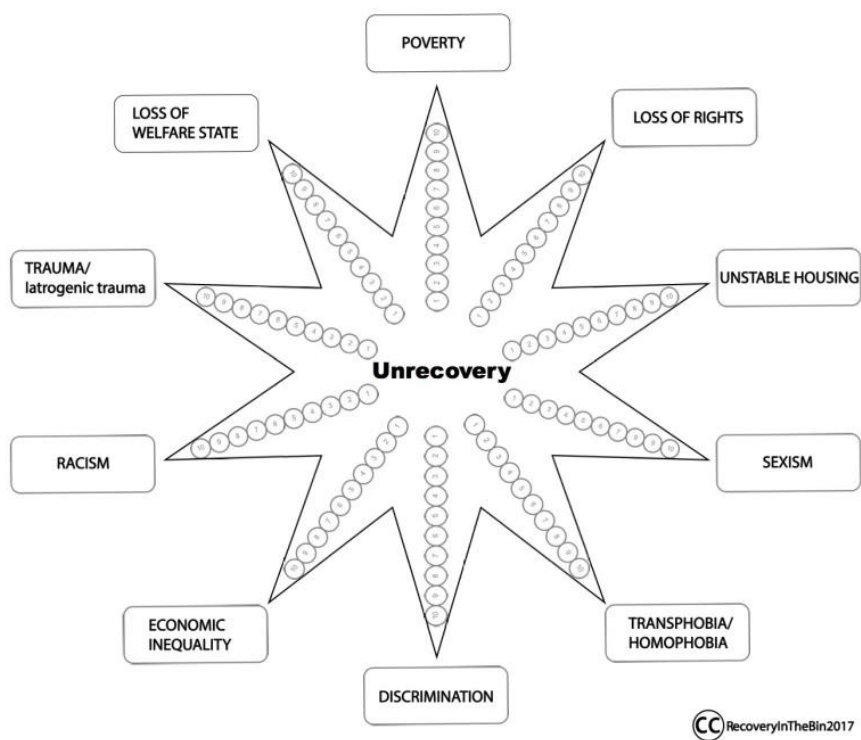
Source: Recovery in the Bin – www.recoveryinthebin.org

4 Alleviating suffering

In Bradford, a peer support worker, Anna, described her experience of visiting Haven, The Cellar Trust's crisis support service: Anna had found herself in crisis when she moved away from her home and relationship for work. 'I thought I was a rubbish mum, a rubbish partner, a rubbish friend.' When Anna returned to work after a holiday, her employer asked her to step down. She started drinking and taking tablets. When the occupational health nurse came to visit her at home, she hadn't showered for weeks, she was covered in scratches and she was wearing the same pyjamas she had been wearing for a week. NHS staff encouraged her to contact the Haven service:

> *Haven called me back and offered me an appointment that day at 4pm. I tried to make excuses not to go but my son brought me. It was a cold winter's day in January but I came in a vest top and pyjamas. I can't remember getting there but remember being sat on a sofa and seeing two people. I wasn't expecting to say much, I wanted them to hate me and tell me that I was wasting their time but nothing that I told them shocked them. They didn't judge me on what I was wearing, what I did, where I came from, they didn't tell me everything would be ok, they were just listening to me. There was so much kindness, empathy and understanding. The worker understood, she made me laugh and I felt so safe.*

Mark Trewin, the service manager for mental health at Bradford Council, described how services before Haven supported people in crisis:

> *We had huge numbers of people accessing crisis services. When we looked at the top 25 people using these services, we realised that many were the same people who turned up repeatedly in A&E, the same people hanging around the town centre causing trouble, the same people triggering police call-outs and getting anti-social behaviour*

orders. We also realised that we had been treating these people cruelly. They annoy us, they get on our nerves, and we tend to get rid of them: 'It's not you again, there is nothing wrong with you, I'm not treating you, you never get better'. They didn't like us very much either.

We are in a powerful position and we didn't always use that power well. Mental health professionals get into a rut. The job is overwhelming and people go into survival mode. Having a hard-bitten nurse come out to see you in the middle of the night and give you a hard time for being a pain in the arse is not a very therapeutic way of working.

Bradford's two voluntary sector centres, Haven and the Sanctuary, aim to provide a safe, calm space for people in crisis. The services are led by peer support workers with lived experience of mental health problems. People who enter Haven have an initial session with a peer support worker, a 24-hour follow-up, and might then come in for two or three further sessions or join a peer support group. There is a nurse on site from the NHS intensive home treatment team and a social worker from the local authority, although they are rarely called into the room. The results are impressive: people report significant reduction in distress; it has contributed to a reduction in people attending A&E; and it has helped Bradford to avoid out-of-area placements in the past three years (Ivory 2018; NHS England n.d.).

For Kim Shuttler Jones, Chief Executive of The Cellar Trust:

What's overwhelmingly clear is that people just want a safe space to come and feel listened to and understood. It's really basic stuff about human kindness and empathy. It makes a massive difference if the people delivering the service have lived experience. There's a different power dynamic. We find that people will disclose things to us and behave very differently to when they are with a clinical member of staff. Elsewhere, given pressures of the NHS, you get your 10-minute GP appointment, your overwhelmed CPN [community psychiatric nurse]

> *with a huge caseload… With all the will in the world, it is very hard in*
> *statutory services to create services that work in this way.*

Our current statements of objectives and desired outcomes of care for mental health services are silent on the task of alleviating suffering. For example, the *Five year forward view for mental health* and the NHS long-term plan make no reference to the task of alleviating suffering, only to treating and addressing the effects of health conditions (NHS England 2019, 2016). Neither the clinical frameworks nor the recovery frameworks discussed in previous sections focus directly on the alleviation of suffering, concerning themselves instead with the signs and symptoms of disorder, people's functioning and whether they have the necessary capabilities and resources to recover.

Yet alleviating suffering appears to be what services such as Haven are doing. The peer support workers we met appeared to have a particular gift in connecting with people in distress. They were often from the same communities as the people they served, with experience of similar problems, and perhaps less likely to make tacit moral judgements. The peer support workers at Haven join people in moments of crisis, bearing witness to their suffering, authorising and legitimising their accounts of what has happened to them. As in Anna's story, part of what they do appears to be reconnecting people with humanity, reminding them that just because they have hit rock bottom, they are not some sort of freak but still fully human.

Some professionals might argue that, in addressing the symptoms of mental disorder, they will address the suffering that comes with it. However, there is extensive research on the distinctions between being afflicted with a physical or mental disorder and suffering. It is possible for services to treat disease in ways that either reduce or exacerbate suffering. The 2018 Review of the Mental Health Act (1983) highlighted scope for health services to either use drug treatments to suppress psychotic symptoms in ways that preserve life and alleviate suffering, or in ways that increase suffering significantly. This is why many have argued that medicine must attend directly to both the treatment of disorders and the alleviation of suffering, rather than assuming

that the former will automatically address the latter (Independent Review of the Mental Health Act 1983 2018; Good 2008; Cassell 2004; Kleinman 1989).

If our current objectives and outcomes disregard the alleviation of suffering, there has also been limited attention to the things that increase it. We rely on a Freedom of Information Act request for data on the use of restraint, one which revealed high and growing use (Greenwood 2017). The Independent Review of the Mental Health Act 1983 (2018) also highlighted the inadequacies of current data on the use of restraint. In 2018, the Secretary of State for Health asked the Care Quality Commission (CQC) to carry out a review of the use of restraint, prolonged seclusion and segregation for people with mental health problems. One key line of inquiry is to assess how many people with mental health problems are subject to these interventions. Until 2016, there was no reporting of the use of out-of-area placements that tear people from their families and support networks.

5 Recovering hope

During our visit to NAViGO in Grimsby, we were shown around by a service user, Maria, who is now also a volunteer. Maria had 'selective mutism' – she didn't talk – for her childhood and a large part of her adult life, and had spent years in inpatient services. This is what she told us:

> When I was born, my mum suffered postnatal depression so she couldn't bond with me. She saw to my basic needs such as food and water, but there was no interaction and she was unable to speak to me until I was about 16. That had an effect on me. I hardly spoke to my family. Then, on the day I started school, I cried and the teacher smacked me and told me not to make another sound. So I didn't speak all the way through school either. At school, I was abused by that teacher and some men that she brought in. I started self-harming and carried on doing it until about two years ago.

> In 2015, I was on the ward again. I had been there for about seven months. I was originally sectioned because I was suicidal and self-harming daily. But the reason I was there for so long was because I couldn't talk or make eye contact in the reviews, so they couldn't tell how I felt. Then in September that year I was asked if I could attend the therapeutic community. If I'm honest, I only attended in the hope it would get me off the ward. It was a real struggle at first and I dreaded each day. If somebody just caught my eye I had to leave. Then as time went on I found I was staying more and more.

> At the same time, I was beginning to trust the staff because they were always honest with me and always did what they said. In the therapeutic community, every minute is a learning curve, whether it's eating together, cooking or just sitting together sharing and listening. Even if someone is in crisis, it is all used to help us see ourselves in

others, how our past has affected our lives, but also how we can break free and move towards the life we want.

I have seen people change so much you had to be there to believe it. I have changed beyond my own belief. I can eat and drink with others. I can talk to almost anyone. I can trust people and I'm now able to help others. Best of all, I have reconnected with a lot of my family and made friends. But best of the best, I have a brilliant relationship with my son and my granddaughters. I love having long cuddles and being close to them, and now when I look upwards instead of dark clouds I can see the beautiful sky and I love life.

When Maria stopped speaking, we were all in tears. In this short period together, it felt as if we grieved collectively for the trauma of Maria's childhood and the loss of a large part of her adult life. Over a longer period, it is possible that this process of mourning, between Maria and staff at NAViGO, may have helped her in some degree to come to terms with what has happened to her and may have helped to alleviate her suffering. It also felt that this authentic shared experience was the foundation for a truly humane caring relationship.

In telling her story, a person who did not have a voice for large part of her life was also now making her voice heard. Maria's narrative appears in part to be an act of sense-making, assembling events, piecing together the range of contributing factors and tracing the patterns and cycles of chronic illness. At the same time, staff at Off the Record would say that this is a political act, calling out the astonishing range of institutions – postnatal services, school, the justice system, mental health services – that have badly failed her.

Our guess is that Maria's story was long in the crafting. It is surely the result of careful dialogue – negotiation even – between Maria, her carers and the other collaborators in the therapeutic community on an appropriate framing of her life, one that has authenticity for Maria, has therapeutic value, and helps

her move forward. If so, it seems possible that this negotiation – genuine co-production – might also hold some of the secrets to a humane relationship.

Maria's narrative hints at the role played by staff at NAViGO and by the therapeutic community in helping her to envision new possibilities for her life: what a different future might look like. Her narrative moves from sense-making to grief to a form of reconciliation, including in the re-establishment of her ties with her family. There is a new sense of purpose: helping others with similar challenges and hugging her grandchildren.

During our visit, Mike Reeve, NAViGO's Director of Operations, introduced us to another service user, David, who had learning disabilities and had spent years in out-of-area rehabilitation services. When NAViGO took control of the out-of-area budget for Grimsby, staff brought David back to their services and asked him what he really wanted to do. It was the first time in years spent in institutions that anyone had asked him. David said he would like to visit his favourite football team, so the staff booked train tickets and they went on a tour of the stadium. When we met, he talked enthusiastically about how he was managing his diabetes and preparing to move into his own flat.

Our main objective in recounting these stories is to highlight the range of purposes that mental health services might serve in supporting people with severe mental health problems. Rather than simply administering medical treatment or even helping people acquire the resources and capabilities for a better life, NAViGO appears to have helped Maria to make sense of what has happened to her, to grieve for lost years, to achieve some sort of (albeit extremely partial) restitution for abuses done to her, to find her voice, to exercise choice, to recover agency in the world, and perhaps to become a political actor. NAViGO has also played an important role in helping Maria and David to recover hope – the belief that they have the possibility of living fulfilling lives.

Another objective is to highlight the individual nature of people's experience of mental health problems. While they might share a diagnosis, people's

experiences of coping with mental health problems are individual in nature, wrapped up in the damaged childhoods, difficult family life, traumatising incarcerations or other chapters of their lives. People's objectives for coping with or recovering from mental illness are also different. For some, the desired outcomes might be completing education, starting a career and recovering independence; for others, it might be visiting their football team, living semi-independently or being a valued grandmother.

6 End note

The tensions between professionals and users of mental health services stem from differences in perspective on issues of fundamental importance, not least our understanding of what it means to suffer from mental illness and the role of health and care services in addressing it. The professionals in health and care services have tended to frame mental illness as generalised problems amenable to generalised solutions – a medical diagnosis and a set of social factors, much the same from one patient to the next, amenable to a common set of off-the-shelf solutions: medical treatment for the disorder, support for housing, a training course to get back to work, for example. Service users do the opposite, seeing mental illness not as a diagnosis – one that they share with other people – but a unique personal experience, and one that is inextricably wrapped up in every feature of themselves and every aspect of their lives.

The narrow lens that professionals in the health and care system have adopted has led to a narrow definition of objectives for services and desired outcomes of care. The frameworks used to measure clinical outcomes in mental health services, such as GAD-7 and PHQ-9 (used to measure anxiety and depression), focus largely on alleviating the medical signs and symptoms of mental ill health. The broader frameworks to support recovery consider other requirements needed to improve wellbeing – for example, employment and housing. Yet people struggling with mental health problems appear to care about a broader range of outcomes still. In moments of crisis, they turn to services not just for a diagnosis or for medical care, or support in developing resources and capabilities, but for sanctuary, to alleviate suffering, to help make sense of what has happened, to grieve, to recover voice, to rekindle hope, to address the stigma that comes with a mental health diagnosis, and perhaps many other important things besides.

This paper has argued for mental health services to adopt this broader perspective on their purpose, as a basis for reconciliation with service users and a foundation for delivering more humane and effective care. For some managers and clinicians, there may be attractions in pursuing a narrow set of measurable objectives – for example, clinical or social outcomes and efficiency in delivering them. For many others, services that fail to focus on broader 'humanitarian' objectives such as alleviating suffering or rekindling hope – dismissing them as peripheral tasks or delegating them to the lowest rungs in the hierarchy – are turning their backs on the purpose of health care.

In one mental health ward we visited, there was a strong stench of faeces from a faulty sewage system. It triggered a powerful urge to escape – an option that was not available to the patients. For the most part, NHS mental health services are not the sort of places people reading this paper would want to visit in a moment of profound personal crisis. Many are noisy, frightening places. There is linoleum on the floor. The windows are glued shut. There are few quiet spaces where you can take refuge. Few people working in mental health services would argue against trying to alleviate suffering or rekindle hope; indeed, many are attempting to do precisely that. Yet the priorities of the day are visible in the environments we have created: ensuring hygiene, avoiding infections and minimising risks, rather than providing sanctuary, alleviating suffering, recovering voice or rekindling hope.

We do still need to measure the performance of mental health services. We cannot return to the recent dark ages where large numbers of people spent years in services without rehabilitation. We need to gather evidence on the effectiveness of services in alleviating the symptoms of mental disorder, helping people to develop resources and capabilities, and supporting recovery. We need to ensure that certain procedures are respected – for example, carrying out physical health checks for people with mental illness. We also need to track how long children have to wait to access services, the number of people in out-of-area placements, and the number of times services use face-down restraint, as a basis for making improvements. The argument is

that the pursuit and measurement of these important objectives should not distract from the other purposes of health and care that matter to service users.

One question that this paper raises – but does not answer – is whether we could define and measure more precisely these 'humanitarian' outcomes of care (such as alleviating suffering or recovering hope). Approaches have been devised to measure similar concepts such as compassionate care. However, there are also reasons for scepticism – not least because of the many different dimensions, discussed above, that humanitarian care can take. Previous research for The King's Fund was similarly ambivalent about the possibility of measuring the quality of therapeutic relationships: 'The therapeutic relationship is something for which objective, valid and reproducible metrics are difficult, if not impossible, to develop' (Greenhalgh and Heath 2010). If this is the case, there is surely a risk of overemphasising the tangible, measurable, more scientific dimensions of health and care, at the expense of the less tangible, less easily measurable, humanitarian dimensions of care.

While there are good arguments for measuring clinical outcomes, there is surely also good cause to view some with a degree of ambivalence. While it might be politically expedient to trumpet a 50 per cent recovery rate for people who participate in brief national therapy programmes, do the bold statistics really tally with the complexities of living with mental health problems? The impressive services we visited combined collection of statistical data with other evidence, including documenting service users' experiences. Interviewees suggested that this provided useful insight into the effectiveness of services. While they lack statistical validity, these stories may help staff to strike the right balance between different objectives that are amenable to different forms of evidence, and trace the finer delineations of humane, effective care.

Even if we could find a way to measure all the relevant outcomes, another question raised by this paper is whether measurement in pursuit of improved

performance could obstruct rather than support the delivery of humane care. This paper provides some anecdotal evidence that the measurement of outcomes, coupled with rigid formulaic approaches to delivering care, can do just that. We are far from the first to raise the possibility. To quote again from the earlier report by The King's Fund, 'some have argued that the quest for standardised "quality metrics" – and the increasing tendency to audit and performance manage practitioners around these – has inadvertently driven down the quality of the therapeutic relationship' (Greenhalgh and Heath 2010). This suggests the need for greater care in the use of measurement tools to avoid further bureaucratising interactions with patients.

At the heart of this debate is the tension between the population health perspective and concern for the individual in health and care. Should we focus on improvements in the overall health and wellbeing of the population, as measured by the number of people who have stopped smoking, the number of people with a healthy weight, or the number of people in employment? Or should we focus on delivering responsive care that is tailored to individuals, attending to their personal needs and aspirations? Both are laudable objectives, and the simple answer is that we should try to do both, but they do not sit entirely comfortably together. Some service users and professionals clearly believe that the balance has shifted too far towards the pursuit of generalised outcomes for the population rather than attending to the individual. Any approach to outcomes that loses sight of the individual is surely part of the problem, rather than the solution, and unlikely to lead to humane or effective care.

Our overriding impression from our conversations and visits to services was of the profoundly personal nature of mental illness. While we might attach diagnostic labels to people, their experience of their illness, its impact on their lives and the nature of their suffering are unique. The approaches that services adopt to support people such as Maria may be successful one day and not the next. The definition of what might constitute a successful outcome is changing and uncertain. As Atul Gawande has argued, the heroism

of health services for people with serious chronic conditions is often the determined, pragmatic search for small improvements in wellbeing, rather than the frustrating, self-defeating pursuit of a cure (Gawande 2017). If this is true, there can be no simple formulas for defining value for many people with mental illness, any more than there are likely to be pat, mechanistic formulas for creating it.

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Appendix: interviews and site visits

At the start of this project, we held interviews with a broad range of stakeholders with experience of and insights into mental health services. These included: service users or former service users working within academia or mental health charities; representatives of national mental health charities; the leaders of national voluntary sector organisations delivering mental health services; a small number of politicians with a strong interest in the delivery of mental health services; and senior clinical leaders in mental health.

We also carried out visits to mental health services in Bradford, Bristol, Grimsby and Oxfordshire. While the visits varied, we typically interviewed commissioners, the leaders of key mental health providers and frontline staff responsible for delivering mental health services. We also spoke to a significant number of current and former service users at all of the sites.

In Bradford, we visited: the charity Mind's Sanctuary service for people in crisis; The Cellar Trust's Haven service for people in crisis; Bradford's Improving Access to Psychological Therapies (IAPT) service; and Bradford's Child and Adolescent Mental Health Services (CAMHS). We also spoke to representatives from the police and social services.

In Bristol, we visited: Off the Record, a charity that supports a mental health social movement and offers support for children and young people with mental health problems; and Bluebell, a charity that helps families to manage their emotional wellbeing during pregnancy and after birth.

In Grimsby, we visited NAViGO, the social enterprise responsible for delivering a broad range of statutory NHS and social services for people with mental

health problems. We visited its inpatient rehabilitation service, its dementia service, its community psychiatric nursing team, its training and employment service and its garden centre.

In Oxfordshire, we visited: Oxford Health NHS Foundation Trust; the charity Response, which provides education, employment and housing services for people with mental health problems; the charity Mind, which also provides housing services in Oxfordshire; and the social enterprise, RAW, which provides training services and runs a woodworking workshop.

About the author

Ben Collins joined the King's Fund in 2015 as a project director, working for the Chief Executive and across the Fund, including on policy and supporting the NHS in developing new care models.

Before joining the Fund, Ben worked as a management consultant. He has advised central government and the national bodies on a wide range of issues including economic regulation, provider finance, the provider failure regime and new organisational models. He has also worked with large numbers of NHS purchasers and providers on strategic and operational challenges.

In his earlier career, Ben was a fast stream trainee and manager within central government and an advisor at the European Commission. He has academic training in industrial economics and business strategy.