REFORM

Making the right choices

Using data-driven technology to transform mental healthcare

Claudia Martínez
Imogen Farhan

July 2019

#reformmentalhealth

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Acknowledgements

Advisory board

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Dr Tom Foley, Senior Clinical Lead for Data, NHS Digital. Tom is a Child and Adolescent Psychiatrist in Newcastle with a passion for how data can be used to improve care. He is Senior Clinical Lead for Data at NHS Digital, where he has clinical responsibility for the national data collections. He has also been a visitor in the Health Economics Team at Newcastle University since 2010 and is Principal Investigator on the Health Foundation funded Learning Healthcare Project. He is a Fellow of the Faculty of Clinical Informatics. Tom has written policy reviews for The Health Foundation, NHS England, Academy of Medical Royal Colleges, Royal College of Psychiatrists and others. He wrote the chapter on digitising General Practice for the Wachter Review and co-authored a supplementary report on the digital future of mental healthcare for the Topol Review. Tom has also worked with CQC, GMC and various other healthcare organisations. Prior to retraining in Medicine at Newcastle, he was a Management Consultant for PwC and BDO, after studying Software Engineering at Durham and an MPhil focused on Economics and Public Policy at Cambridge.

Maxine Mackintosh, PhD student at the Alan Turing Institute and University College London's Institute of Health Informatics. Maxine's PhD involves using medical records to uncover early signs of dementia. She is interested in how we might make better use of routinely collected data to inform our understanding of health and diseases. Prior to this, she completed a BSc in Biomedical Sciences (UCL) and an MSc in Health Policy, Planning and Financing (LSE & LSHTM). In addition, Maxine is the co-founder of One HealthTech – a community which champions and supports underrepresented groups, particularly women, to be the future leaders in health innovation. She is part of a number of communities including the World Economic Forum's Global Shapers, and the British Computer Society (Health Exec) and DeepMind Health's Independent Review Board.

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The findings of this report were also presented to the National Institute for Health Research (NIHR) Mental Health Specialty Group.

Event

On 4th December 2018, *Reform* held a research roundtable with 21 experts (see appendix for details) to determine the scope of the research project and discuss the ethical implications of implementing data-driven technologies in mental healthcare. We would like to thank the attendees for their contribution to the discussion.

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Executive summary

This report examines the current landscape of data-driven technologies and their applications in mental healthcare, highlighting areas where these tools offer the most potential for the NHS and its patients. It discusses what makes mental health different from other areas of health, and the implications this has for the application of data-driven tools. It examines barriers to implementation, including the limited access to high-quality data and the need to build trust with patients and practitioners. Finally, it proposes ways to move forward.

Going beyond the hype

Mental health is undergoing a 'digital revolution'. While much focus in recent years has been placed on consumer-facing digital solutions, such as mental health apps, evidence of their effectiveness is lacking. In reality, the landscape of data-driven tools in mental health is much broader. A variety of tools and technologies are being piloted and deployed across all stages of the care pathway, from prevention through to monitoring, to support both individuals and populations. Capitalising on the opportunities offered by data-driven technologies will require NHS leaders to cut through the hype surrounding these technologies and build a greater understanding of where the biggest transformational benefits lie.

Why mental health needs a different approach

Mental health presents tensions and 'sensitivities' that create specific challenges for the application of data-driven technologies. Approaches to diagnosis and treatment must be nuanced and contextualised. People living with mental illness face discrimination and stigma, creating barriers to accessing high-quality care, as well as heightened concerns about how patient data is accessed. Capacity to give consent about data sharing in mental health cannot always be guaranteed, and special consideration needs to be given to ensuring data-driven technologies are used in a way that safeguards people's privacy and does not perpetuate discrimination at scale.

What will this mean for the NHS and its patients

Data-driven technologies are often hailed as a solution to the challenges facing mental health services. However, in the short-term their potential lies in relieving the pressure on mental health services by streamlining repetitive tasks and giving practitioners more time to spend on direct patient care. In the long-term, these tools could enable the better delivery of preventative and personalised care, by opening up new types of data collection and analysis to enhance understandings of mental health.

Creating systemic change

Realising the potential for data-driven technologies in mental healthcare depends on accessing robust and high-quality data. It will require the NHS to build a trustworthy system that meets the expectations of patients, healthcare professionals and the public. Efforts must also be directed towards improving current processes for capturing, analysing and sharing data in mental health. However, technology alone will not lead to better care. Delivering sustained change will require the NHS to translate data-driven insights into meaningful clinical interventions. This will hinge on NHS organisations' ability to assess their own readiness for change and consider the full range of factors impacting the long-term adoption and success of data-driven tools.

Recommendations

1. The National Institute for Care and Health Excellence should make guidelines and protocols machine-readable to inform Clinical Decision Support Systems used in mental healthcare. This would make the guidelines more accessible to frontline practitioners and enable the guidelines to be continuously improved in accordance with up-to-date clinical evidence.
2. The Royal College of Psychiatrists, in partnership with the Medicines and Healthcare products Regulatory Agency, should offer short, online training to mental health practitioners, and better publicise existing information about the Medicines and Healthcare products Regulatory Agency's Yellow Card Scheme. This will increase awareness among practitioners about how the Scheme can be used to identify and report issues with medical software, including certified mental health apps.
3. The National Data Guardian should issue guidance for innovators and providers to improve the informed consent process for apps and other patient-facing mental health tools. This guidance should consider the needs of the different user groups accessing mental health services, such as children and young people, older people, and those with high levels of vulnerability.
4. In order to build patient trust and encourage the responsible linkage of data to better understand mental health, the Royal College of Psychiatrists and NHS Digital, in partnership with Health Data Research UK, should develop a template for patient engagement for research initiatives linking mental health data. The patient engagement and governance models used by initiatives such as The Clinical Record Interactive Search System research programme could provide the basis for this framework.
5. The National Institute for Health and Care Excellence, in partnership with NHSX, should update procurement rules to ensure that healthcare technologies bought by the NHS are user-friendly and that data is presented in accessible ways to frontline staff. This would equip practitioners with actionable insights to improve direct patient care.
6. In order to improve understanding of mental health conditions, NHS Digital should develop a repository using data held by NHS organisations to help researchers securely identify suitable participants for mental health research studies and assess the feasibility of research projects at early stages. Similar governance frameworks to the Scottish Health Research Register should be employed.
7. NHS Digital, the Health Research Authority and the Clinical Research Network in England should collaborate with academic institutions to develop curated, 'research ready' datasets. This would make it easier for researchers to analyse and generate insights from data held by NHS organisations to improve the understanding of mental health conditions.
8. NHSX should require all healthcare providers to design interoperable systems and ensure data portability. This would allow data generated from technologies such as wearables and sensors to be transferred across platforms.
9. NHS Digital should harness the potential of the significant volume of clinical data already held by the NHS by linking together the Mental Health Services Dataset, Improving Access to Psychological Therapies and Hospital Episode Statistics Dataset. Linking these datasets would create greater visibility of patients' interactions with the healthcare system, which would allow for the better planning of services and a better understanding of patient outcomes.

10. To promote research that will deepen understanding of mental health conditions, NHS Digital should collaborate with bodies such as the Clinical Research Network in England to make approaches to data linkage more transparent by encouraging researchers to publish the code and methods used to link data in an open source platform. Guidance should be developed to ensure that data protection principles are preserved.
11. In order to assess the feasibility of implementing and scaling-up digital innovations, the seven mental health trusts identified to lead the next wave of digital transformation across NHS mental health services should adopt the Non-adoption, Abandonment, Scale-up, Spread and Sustainability framework. Adopting this framework on this limited scale will also help build the evidence-base for its wider use across the NHS.

Introduction

Mental healthcare is undergoing a "digital revolution."[1] The booming market for mental health apps is the most visible aspect of this transformation, and testament to the public appetite for data-driven mental health support. Despite known gaps in evidence regarding their effectiveness, there are now upwards of 10,000 apps available to download, with one of the most popular apps boasting over 45 million downloads.[2] This reflects the fact that mental health issues are not uncommon: one in four adults will experience a mental health problem each year.[3]

The NHS is keen to catch up. It has recognised that such technologies offer exciting possibilities to deliver "the most advanced health and care service in the world",[4] and has made considerable investments into leveraging the use of technologies in mental healthcare. This includes a £67.7 million funding package announced in 2017 to develop digital mental health services[5] and the Mental Health Global Digital Exemplars programme.[6] *The NHS Long Term Plan* promised to explore the use of digitally-enabled models of therapy for depression and anxiety disorders.[7] NHSX, the new joint organisation for digital, data and technology, has made mental health one of its priority areas, announcing that mental health teams would be provided with technical skills and digital expertise to adopt technological innovations.[8]

These commitments come at a time when NHS mental health services face increasing demand, workforce shortages and service fragmentation.[9] In many parts of the country, patients are waiting an unacceptably long time for assessment and treatment; and there is high variability in terms of the quality of the services provided.[10] Accessing the right treatment at the right time remains a problem for many, particularly for children and young people[11] and those living with severe mental health illnesses.[12] These concerns are all the more significant when considering the human costs of service failures in mental health for users and their families, as evidenced by recent Parliamentary and Health Service Ombudsman research.[13]

In order to take full advantage of the advances in data-driven technology to improve mental healthcare, the NHS must "walk before it runs."[14] While the opportunities offered by mental health apps represent the public face of the digital mental health revolution, the value of data-driven technologies in mental healthcare in fact extends far beyond this. By opening up new types of data collection and analysis, data-driven technologies present opportunities to advance understanding of the causes of mental illness, improve detection and diagnosis, and help redesign services around the needs of patients.

1 Sandra Bucci, Matthias Schwannauer, and Natalie Berry, 'The Digital Revolution and Its Impact on Mental Health Care', *Psychology and Psychotherapy: Theory, Research and Practice*, 2019; Rebecca Cotton, *Using Digital Technology to Design and Deliver Better Mental Health Services: Perspectives from Australia and the USA* (Mental Health Network NHS Confederation, 2019); Amir Tal and John Torous, 'The Digital Mental Health Revolution: Opportunities and Risks.', *Psychiatric Rehabilitation Journal* 40, no. 3 (2017).
2 John Torous et al., 'Towards a Consensus around Standards for Smartphone Apps and Digital Mental Health', *World Psychiatry* 18, no. 1 (2019): 97; Calm Harm, 'About Calm Harm', Webpage, Calm Harm, 2018.
3 NHS England, 'Mental Health', Webpage, January 2019.
4 GOV.UK, 'Matt Hancock: New Technology Is Key to Making NHS the World's Best', Webpage, 6 September 2018.
5 GOV.UK, 'Prime Minister Unveils Plans to Transform Mental Health Support', Webpage, 9 January 2017.
6 NHS England, 'Mental Health Global Digital Exemplars', Webpage, 2019.
7 NHS England, *The NHS Long Term Plan* (NHS England, 2019).
8 Department of Health and Social Care, 'NHSX: Digital Experts Will Be Part of Cancer and Mental Health Teams', Webpage, 4 April 2019.
9 Care Quality Commission, *The State of Care in Mental Health Services 2014 to 2017*, 2018.
10 Ibid.
11 Public Accounts Committee, 'Mental Health: Poor NHS Provision Is Failing Young People', Webpage, 11 January 2019.
12 Rethink Mental Illness, *Right Treatment, Right Time*, 2018, 8.
13 Parliamentary and Health Service Ombudsman, *Maintaining Momentum: Driving Improvements in Mental Health Care*, 2018.
14 Shaun O'Hanlon, 'NHS Tech: Let's Walk before We Run', *NHS Confederation*, 30 April 2018.

This report seeks to ‘cut through the hype’ surrounding data-driven technologies in mental health. It demonstrates why mental healthcare needs a different approach to data-driven technology and, using real-life case studies, highlights areas where data-driven tools have the greatest potential to improve research and clinical practice now, and in the future. It discusses what it is needed to facilitate the successful adoption of these technologies across the NHS more broadly and recommends ways the NHS can build a representative and trustworthy data ecosystem as a necessary first step.

1
Going beyond the hype

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Data-driven technologies are increasingly hyped as 'silver bullets' for the challenges facing the NHS.[15] Much of the focus in recent years has been on the opportunities offered by mobile technologies, however, the value of data-driven technologies in mental healthcare goes well beyond this. A variety of tools and technologies are being piloted and deployed across all stages of the care pathway (see Glossary) from prevention through to monitoring, to support both individuals and populations.

Figure 1: Defining data-driven technologies

Data-driven technologies work by "collecting, using and analysing patient data to support the care of individuals, NHS services, public health, or medical research and innovation".[16] Data-driven technologies are often reliant on large data sets, collected from a variety of sources, including electronic health records (EHRs), clinical trials or data generated by patients themselves, for instance through wearable devices. Analytical methods can then be applied to stratify patients and find associations between risk factors, such as physical health conditions, amongst other applications.

Artificial Intelligence (AI) is a type of data-driven technology that is increasingly being used to generate new insights from data. AI describes a set of advanced technologies that enable machines to do highly complex tasks effectively – which would require intelligence if humans were to perform them.[17] For instance, machines with the capability to reason, plan, learn and solve problems.[18] The term AI covers a variety of approaches, including machine learning, natural language processing, expert systems and robotics, among others. *Reform's* report "*Thinking on its own: AI in the NHS"* offers a classification of common AI methods.[19] (See Glossary for further definition.)

1.1 A 'wild west' of mental health apps?

Across all of healthcare, there is increased interest in using digital tools, such as smartphone apps and wearable sensors, to deliver and augment care. This has been evident in the field of mental health, where the number of mental health apps has grown dramatically in recent years.[20] Whilst most mental health apps are targeted at wellbeing support rather than clinical care,[21] there is an increased interest within the NHS in the use of digital tools to deliver or supplement mainstream interventions, for instance, as part of the Improving Access to Psychological Therapies (IAPT) programme.[22]

Yet, the adoption of apps in mainstream mental healthcare has been slow and hampered by concerns about quality and clinical effectiveness.[23] As argued by one interviewee for this paper, the expansion of apps in the field of mental healthcare has been rapid and largely unregulated, with practitioners and patients left to navigate an increasingly complex and evolving 'wild west' of apps. A recent review of consumer-facing mental health apps shows that, whilst 64 per cent of apps available in commercial app stores claim to diagnose, manage or help ease the symptoms of mental health problems, only 44 per cent of them use scientific language to back-up these claims.[24] Without a sound

15 Denis Campbell, 'The Robot Will See You Now: How AI Could Revolutionise NHS', *The Guardian*, 11 June 2018; Jo Best, 'AI and the NHS: How Artificial Intelligence Will Change Everything for Patients and Doctors', NetApp, 15 November 2018.
16 The Academy of Medical Sciences, *Our Data-Driven Future in Healthcare*, 2018, 13.
17 Professor Dame Wendy Hall and Jérôme Pesenti, *Growing the Artificial Intelligence Industry in the UK* (Department for Digital, Culture, Media & Sport and Department for Business, Energy & Industrial Strategy, 2017).
18 David D. Luxton, 'An Introduction to Artificial Intelligence in Behavioral and Mental Health Care', in *Artificial Intelligence in Behavioral and Mental Health Care*, ed. David D. Luxton (San Diego: Academic Press, 2016), 1–26.
19 Eleonora Harwich and Kate Laycock, *Thinking on Its Own: AI in the NHS* (Reform, 2018).
20 Tal and Torous, 'The Digital Mental Health Revolution: Opportunities and Risks.'
21 Emily Anthes, 'Mental Health: There's an App for That', *Nature* 532, no. 20–23 (2016).
22 NHS England, *The NHS Long Term Plan*, 26.
23 Marlene Lynette East and Byron C Havard, 'Mental Health Mobile Apps: From Infusion to Diffusion in the Mental Health Social System', *JMIR Mental Health* 2, no. 1 (2015); Joyce HL Lui, David K Marcus, and Christopher T Barry, 'Evidence-Based Apps? A Review of Mental Health Mobile Applications in a Psychotherapy Context.', *Professional Psychology: Research and Practice* 48, no. 3 (2017): 199; Pooja Chandrashekar, 'Do Mental Health Mobile Apps Work: Evidence and Recommendations for Designing High-Efficacy Mental Health Mobile Apps', *MHealth* 4 (2018).
24 Mark Erik Larsen et al., 'Using Science to Sell Apps: Evaluation of Mental Health App Store Quality Claims', *Npj Digital Medicine* 2, no. 1 (2019).

evidence base practitioners are unlikely to use these tools or recommend them to their patients.[25] Lack of evidence is not the only challenge. As stressed by several interviewees, implementation within services has often proven problematic. Failure to involve users, clinicians and all relevant stakeholders when designing these tools, lack of understanding of how the solution fits with existing care pathways and systems being incompatible or 'not talking to each other', are cited as key barriers.

There is still a long way to go before the full potential of apps to support mental health services and clinical care is realised.[26] Work is already underway to address some of these issues. For instance, the NHS Apps Library already provides a selection of approved mental health apps.[27] The Department of Health and Social Care's Code of Conduct for Data-driven Health and Care Technology[28] and NICE's Evidence Standards Framework[29] set out the 'rules of engagement' for developers working in partnership with the NHS and define the appropriate level of evidence required to ensure that data-driven technologies are safe, effective and deliver value for money. However, for apps to deliver change on the ground, greater work will be needed to improve research and evaluation, develop appropriate governance arrangements, improve the visibility of the apps that work, and ensure that the tools being developed align with services and care pathways.

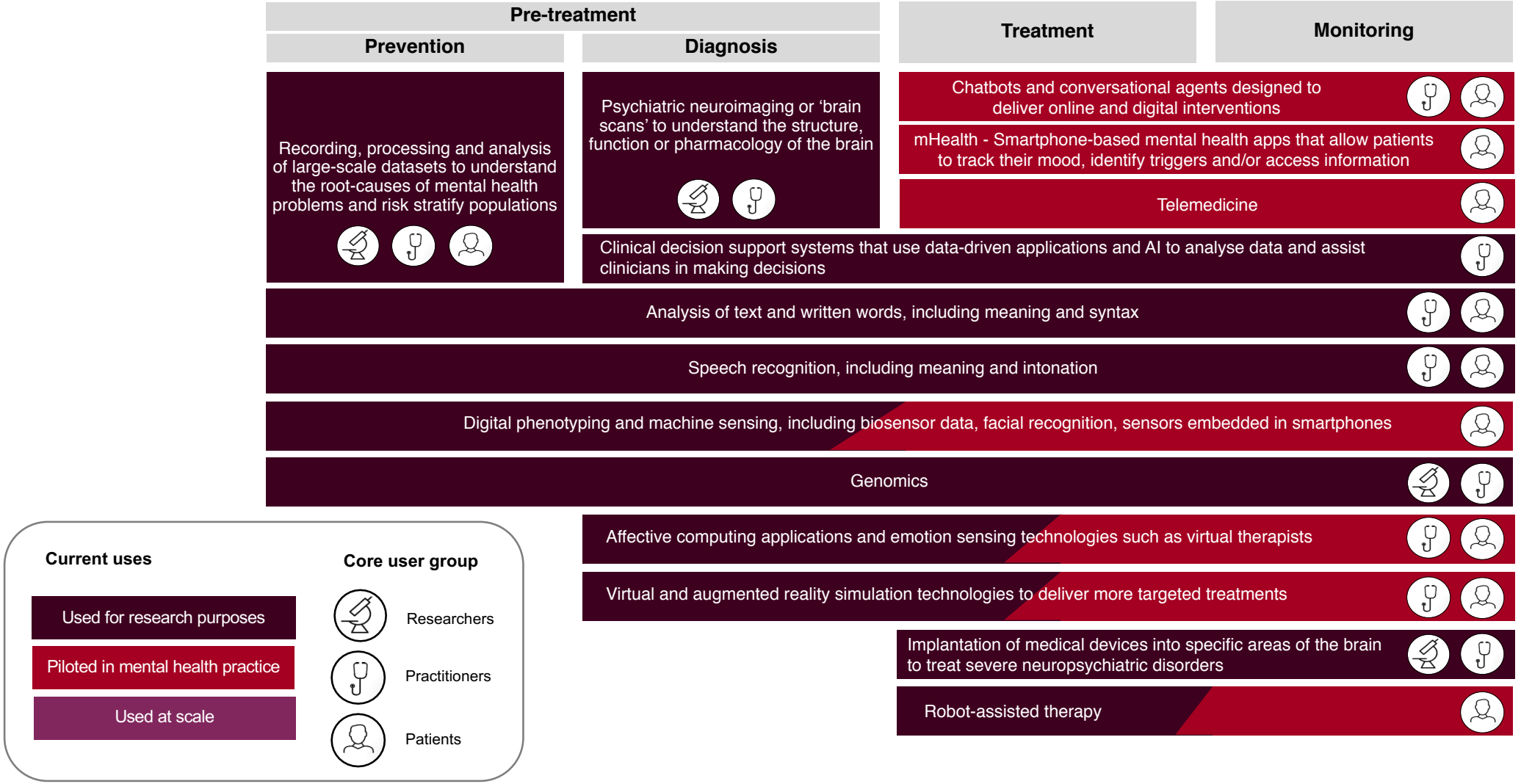
1.2 The wider technology landscape

The landscape of data-driven technologies in mental health is evolving rapidly. A myriad of tools are emerging to help understand the causes of mental illness, develop risk-based approaches to treatment and support, and help practitioners make better-informed decisions. Consumer-facing tools and sensing technologies, including mental health apps, chatbots and wearables, are already being piloted in some parts of the NHS to help patients self-manage their conditions and to support service redesign. Yet, as shown in Figure 2, many of these data-driven innovations are at research stage, and hence not deployed in mainstream mental health practice.

Although not yet implemented at scale, pockets of innovation exist within different parts of the NHS where technologies are being piloted and tested to improve mental health services. Specific applications and examples of such initiatives are discussed in Chapter 3 of this paper.

25 John Torous et al., 'Creating a Digital Health Smartphone App and Digital Phenotyping Platform for Mental Health and Diverse Healthcare Needs: An Interdisciplinary and Collaborative Approach', *Journal of Technology in Behavioral Science*, 2019; Stephen M Schueller, Jason J Washburn, and Matthew Price, 'Exploring Mental Health Providers' Interest in Using Web and Mobile-Based Tools in Their Practices', *Internet Interventions* 4 (2016).
26 Tal and Torous, 'The Digital Mental Health Revolution: Opportunities and Risks.'
27 NHS, 'NHS Apps Library', Webpage, 2019.
28 Department of Health and Social Care, *Code of Conduct for Data-Driven Health and Care Technology*, 2018.
29 National Institute for Health and Care Excellence, *Evidence Standards Framework for Digital Health Technologies*, 2018.

Figure 2: Applications of data-driven technologies in mental healthcare



Source: *Reform* research.

2
Why mental health needs a different approach

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Data-driven technologies offer significant potential to improve care. However, as argued by experts interviewed for this paper, successfully deploying these tools into mental health practice requires consideration of the specific tensions and 'sensitivities' presented in mental health.

2.1 The importance of nuance and context

The dynamic nature of mental health problems means that, unlike other areas of healthcare, diagnosing and treating these conditions is not straightforward.[30] In fields such as physical health, practitioners can make use of measurable indicators and clinical tests to diagnose patients and decide the best course of treatment. However, in mental health there are few such 'tests' and the process of obtaining reliable diagnosis is often lengthy and requires extensive assessment. Mental illness is inherently complex involving biological, psychological and social factors.[31]

Mental health symptoms may not be clear-cut and may overlap between conditions, which are often co-morbid (see Glossary).[32] This poses challenges for designing meaningful and effective interventions. Indeed, the complex, and sometimes chronic, nature of some disorders calls for tailored and flexible care plans.[33] Additionally, people's subjective experiences of their mental illness can play an important role in the recovery process and the effectiveness of treatments.[34] In many cases, what might prove successful for one patient might not for the other. For instance, in the United States only one third of patients suffering from depression benefits from the first antidepressant treatment they are prescribed.[35] In the UK, a fifth of patients undergoing antidepressant treatment will show no reduction in symptoms in the first four weeks, but might react to treatment if given more time.[36] This further exemplifies the difficulties of 'unpicking' any biological underpinnings of positive or negative responses to treatment and the individual nature of mental health conditions.

Considering the challenges in understanding the nature and causes of mental illnesses, it is unsurprising that no set definition for mental health exists.[37] In mental health practice, conditions are often categorised, and treatment decided, based on the symptoms exhibited by patients.[38] The multidimensionality of psychological symptoms may be compounded by different, and sometimes conflicting, interpretations of the term 'mental health'. Most often, mental health is used as an "umbrella term" to describe a spectrum from mental health problems, conditions, illnesses and disorders through to mental wellbeing or positive mental health.[39] Indeed, mental illness can include mood disorders, such as depression and anxiety, psychotic disorders, such as schizophrenia, behavioural disorders, personality disorders, neurodevelopmental disorders, dementias and others.[40] Diagnostic tools and frameworks have been developed over the years to help practitioners better identify and treat these problems. In the UK, the International Classification of Diseases (ICD) is often used to classify mental disorders.[41]

30 Lee Anna Clark et al., 'Three Approaches to Understanding and Classifying Mental Disorder: ICD-11, DSM-5, and the National Institute of Mental Health's Research Domain Criteria (RDoC)', *Psychological Science in the Public Interest* 18, no. 2 (2017).
31 Rangaswamy Srinivasa Murthy et al., *The World Health Report. Mental Health: New Understanding, New Hope* (World Health Organization, 2001), 4.
32 Chris Naylor et al., *Long-Term Conditions and Mental Health: The Cost of Co-Morbidities* (The King's Fund and Centre for Mental Health, 2012).
33 Clark et al., 'Three Approaches to Understanding and Classifying Mental Disorder: ICD-11, DSM-5, and the National Institute of Mental Health's Research Domain Criteria (RDoC)', 75,97.
34 Wouter Vanderplasschen et al., 'Mental Health, Recovery, and the Community', *The Scientific World Journal*, 2013.
35 Tania Carrillo-Roa et al., 'Common Genes Associated with Antidepressant Response in Mouse and Man Identify Key Role of Glucocorticoid Receptor Sensitivity', *PLoS Biology* 15, no. 12 (2017).
36 Jonathan Henssler et al., 'Trajectories of Acute Antidepressant Efficacy: How Long to Wait for Response? A Systematic Review and Meta-Analysis of Long-Term, Placebo-Controlled Acute Treatment Trials.', *The Journal of Clinical Psychiatry* 79, no. 3 (2018).
37 British Medical Association, *Breaking down Barriers – the Challenge of Improving Mental Health Outcomes*, 2017.
38 David Adam, 'Mental Health: On the Spectrum', *Nature News* 496, no. 7446 (2013).
39 Faculty of Public Health and Mental Health Foundation, *Better Mental Health For All: A Public Health Approach to Mental Health Improvement* (London, 2016).
40 Mental Health Foundation, 'What Are Mental Health Problems?', Webpage, 2019.
41 World Health Organization, *How to Use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF)* (Geneva, 2013).

Fundamental questions remain as to the relationship between mental illness and what is commonly known as 'mental wellbeing'.[42] Mental illness refers to diagnosed mental disorders as per the ICD criteria. Mental wellbeing refers to the absence of mental illness or mental disorder and the presence of positive mental health, typically measured as life satisfaction, good quality of life and happiness.[43] There is consensus that mental illness and mental wellbeing are interdependent, and that it is possible for someone to have a mental disorder while also experiencing high levels of wellbeing (and vice versa).[44] Furthermore, these relationships might vary depending on the mental disorder.

2.2 Stigma and stereotyping

People living with mental illness are often subject to prejudice, exclusion and discrimination from society. Whilst public attitudes towards people with mental health problems in England have improved in recent years,[45] one in three people report discrimination from healthcare practitioners.[46] Discrimination within services creates barriers to access and quality of care, especially for user groups traditionally more affected by stigma. For instance, evidence shows that discrimination faced by people from black and minority ethnic communities[47] has resulted in reticence to access pre-crisis services.[48] Practitioner bias might also lead to 'diagnostic overshadowing', namely the provision of "worse physical healthcare" for those with mental health problems.[49] Fear of not being taken seriously can result in people failing to disclose that they have mental health symptoms to their GP, or discourage them from seeking support altogether. Attempts to 'join-up' the NHS rarely take account of minority communities.

2.3 Autonomy versus protection

Discussions of unequal power relationships between patients and professionals have dominated the healthcare debate for decades. However, nowhere is this more apparent than in mental healthcare, where long-standing power imbalances have resulted in disempowerment and exclusion for some people.[50] Mental health professionals not only have a duty of care towards their patients but also towards society. This societal duty of care means that mental health is one of the few disciplines where professionals are granted powers to detain and treat someone without their consent.[51] This has significantly shaped the narrative around mental health services, where notions of power, self-agency and human dignity have been historically prevalent.[52] These concerns must be considered when designing and deploying data-driven technologies. Thoughtfully designed, data-driven technologies can help address power imbalances[53] and reshape the patient-professional relationship by reducing asymmetries of information and granting patients greater access to valuable information about their conditions. For this to happen, patients must be 'kept in the loop' and meaningfully involved in decisions about how technology can be best used to support decisions about their treatment.

42 Felicia A. Huppert, *The State of Wellbeing Science*, Wellbeing: A Complete Reference Guide, 2014.
43 Ibid.
44 Scott Weich et al., 'Mental Well-Being and Mental Illness: Findings from the Adult Psychiatric Morbidity Survey for England 2007', *British Journal of Psychiatry* 199, no. 1 (2011).
45 Sara Evans-Lacko et al., *Effect of the Time to Change Anti-Stigma Campaign on Trends in Mental-Illness-Related Public Stigma among the English Population in 2003–13: An Analysis of Survey Data* (Lancet Psychiatry, 2014).
46 Paul Corry, *Stigma Shout: Service User and Carer Experiences of Stigma and Discrimination* (Time to Change, 2008).
47 Ibid.
48 Department of Health and Social Care, *Modernising the Mental Health Act. Increasing Choice, Reducing Compulsion. Final Report of the Independent Review of the Mental Health Act 1983*, 2018.
49 Elizabeth Corker et al., 'Experiences of Discrimination among People Using Mental Health Services in England 2008-2011', *The British Journal of Psychiatry* 202, no. s55 (2013).
50 Ingrid Larsson and Henrika Jormfeldt, 'Perspectives on Power Relations in Human Health and Well-Being', International Journal of Qualitative Studies on Health and Well-Being, 2017; Richard Laugharne and Stefan Priebe, 'Trust, Choice and Power in Mental Health', *Social Psychiatry and Psychiatric Epidemiology* 41, no. 11 (2006).
51 HM Government, 'Mental Health Act 2007' (2007).
52 Department of Health and Social Care, *Modernising the Mental Health Act. Increasing Choice, Reducing Compulsion. Final Report of the Independent Review of the Mental Health Act 1983*, 17.
53 Emanuelle Burton et al., 'The Heart of the Matter: Patient Autonomy as a Model for the Wellbeing of Technology Users', 2018.

3
What will data-driven technologies mean for the NHS and its patients?

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Data-driven technologies can bring benefits to patients, practitioners and the wider health system. In the short to medium-term, much of this potential lies in relieving the pressure on mental health services by giving practitioners more time to spend on direct patient care and providing new ways to deliver low-intensity, ongoing support. In the long-term, data-driven technologies could lead to more preventative and precise care by allowing for new types of data-collection and analysis to enhance understandings of mental health.

3.1 Giving back time

In the immediate term, much of the potential for data-driven technologies in mental healthcare lies in streamlining repetitive tasks and back-end operational processes to enable practitioners to spend more time with their patients.[54] This could enhance patients' experiences of care and promote greater access to services.[55]

3.1.1 Tracking symptoms

The time when a patient interacts with a clinician can only give clinicians a small snapshot of someone's mental health. Monitoring symptoms over time and accurately sharing this information with clinicians is therefore crucial to ensure more accurate diagnosis and more effective treatment.[56] However, current methods for patients to monitor their symptoms, such as mood diaries, can prove time-consuming, unreliable and can present a partial picture of a person's mental health.[57] Practitioners interviewed for this paper also stressed that these worksheets can "take up huge amounts of time" in a consultation to process and analyse.

By enabling patients to record their symptoms on their smartphone, digital technologies are facilitating a shift away from paper records.[58] This form of monitoring can be more convenient for patients who are 'digital natives'. Additionally, by enabling patients to record their symptoms instantaneously and within their natural environment, and to be reminded to do so via nudge reminders, digitising this process could lead to more reliable, real-time data collection.

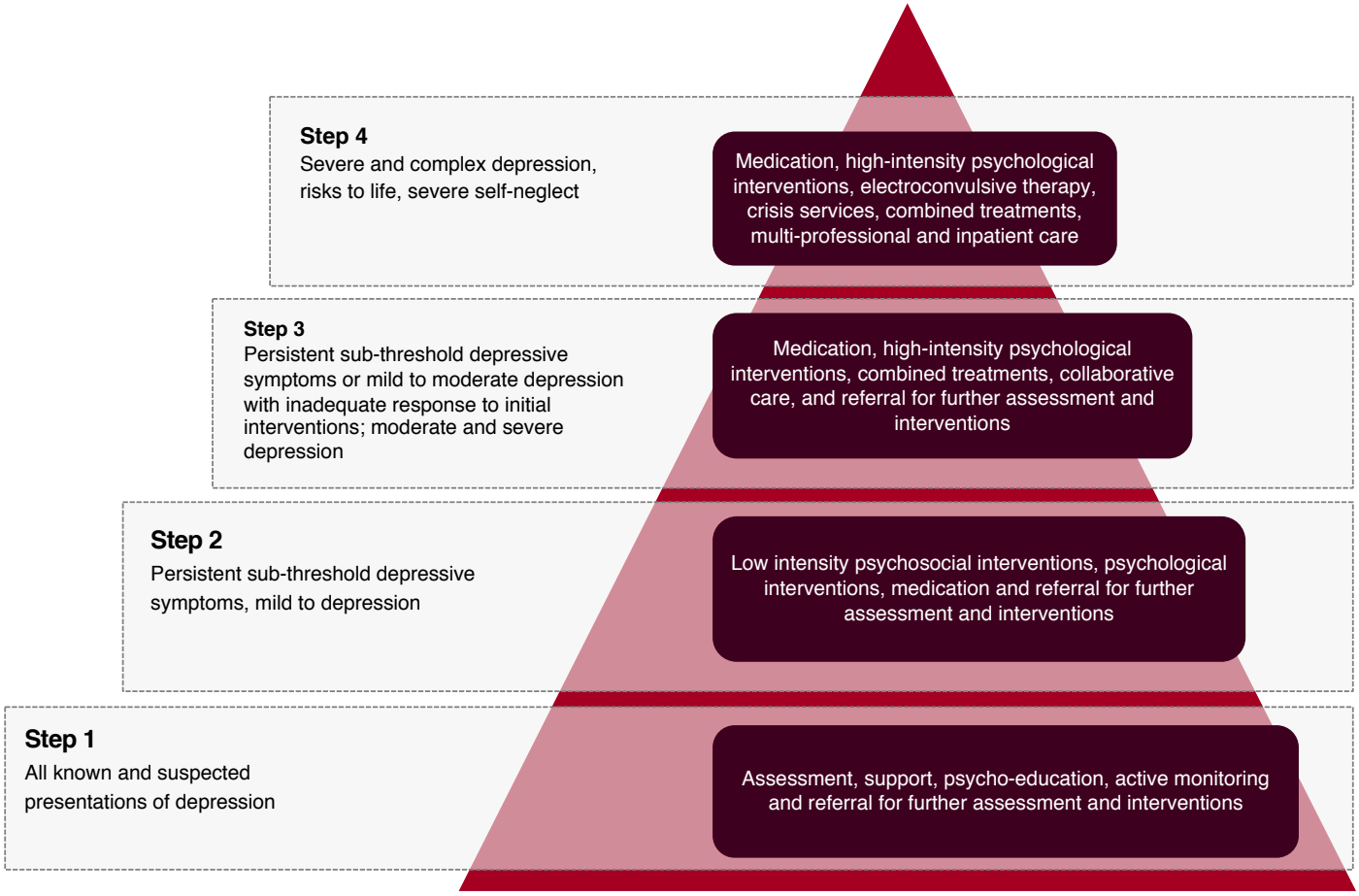
For clinicians, information presented in digitised, computer-readable formats could be more accessible and provide some initial analysis. For example, graphs which show peaks and troughs in mood overtime can make it easier for patients and clinicians to pinpoint actions which improve or worsen a patient's condition. There is also potential for practitioners to view these mood diaries in real-time and alter the intervals between appointments accordingly. As discussed in Chapter 5, however, this requires tools that are interoperable with clinical systems, and that data are easily extractable and collected according to clinical standards.

3.1.2 Streamlining triage

Data-driven technologies could also help digitise existing processes used to triage patients to appropriate levels of support, and achieve a stepped-care approach to mental health treatment as shown in Figure 3.[59] The core principle behind this model is that people should be offered the least intrusive intervention appropriate for their needs first, with people being stepped-up to specialised or more intensive treatment as clinically required.[60]

54 Tom Foley and James Woollard, *The Digital Future of Mental Healthcare and Its Workforce: A Report on a Mental Health Stakeholder Engagement to Inform the Topol Review* (NHS, 2019).
55 Michelle Farr et al., 'Implementing Online Consultations in Primary Care: A Mixed-Method Evaluation Extending Normalisation Process Theory through Service Co-Production', *BMJ Open* 8, no. 3 (2018).
56 Foley and Woollard, *The Digital Future of Mental Healthcare and Its Workforce: A Report on a Mental Health Stakeholder Engagement to Inform the Topol Review*.
57 Ibid.
58 John Torous, Patrick Staples, and Jukka-Pekka Onnela, 'Realizing the Potential of Mobile Mental Health: New Methods for New Data in Psychiatry', *Current Psychiatry Reports* 17, no. 8 (2015).
59 Luxton, 'An Introduction to Artificial Intelligence in Behavioral and Mental Health Care'.
60 The National Collaborating Centre for Mental Health, The Improving Access to Psychological Therapies Manual, 2018.

Figure 3 Stepped Care Model for treating depression



Source: National Institute for Health and Social Care Excellence (NICE).

In primary care, questionnaires are often used to screen and assess people who visit their GP about their mental health. Clinicians then analyse the responses to triage people to appropriate support. Interviewees for this paper noted that these forms can be "astonishingly long" and off-putting for patients. Research is underway to understand how data-driven tools can be used to improve patients' experiences of triage and reduce the time spent by staff on these processes. For example, one study has developed a chatbot which asks questions typically used in mental health questionnaires in an online, conversational format. The bot is designed to replicate NICE guidelines,[61] and the data gathered is then given to a clinician to assess. Crucially, this is not a tool to enable triage, but to gather data. By enabling patients to answer these questions at home it could increase engagement from certain groups, such as young people, who are least likely to access mental health support due to stigma.[62] Indeed, one interviewee for this paper noted the advantages for data-driven technologies in mental healthcare may "be psychological, not just technical."

There have been discussions about the potential for chatbots to assist in the triage process itself, rather than simply gather data for a clinician to triage.[63] Using natural language processing, for example, bots could analyse text and voice inputs for emotional and suicidal ideation and provide risk ratings for clinicians. This could help break down

61 Eric Topol, The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. An Independent Report on Behalf of the Secretary of State for Health and Social Care (Health Education England, 2019).
62 Sarah Clement et al., 'What Is the Impact of Mental Health-Related Stigma on Help-Seeking? A Systematic Review of Quantitative and Qualitative Studies.', Psychological Medicine, 2014.
63 Eric Topol, The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. An Independent Report on Behalf of the Secretary of State for Health and Social Care (Health Education England, 2019).

some of the barriers in accessing treatment. There is research showing that, in some circumstances, patients are more likely to disclose personal details to AI-powered conversational assistants rather than to an actual clinician.[64]

In its current form, however, natural language processing is too rudimentary to be used in clinical practice. Crucially, the majority of interviewees argued it cannot yet capture the nuances required to triage mental health symptoms accurately. One interviewee described how "one patient may never mention the word suicide but may be in need of urgent medical attention. In comparison, another may openly talk about suicide and be at a lower level of risk."

Technical barriers also persist. A comprehensive library of the full spectrum of language associated with a mental health crisis, such as having suicidal thoughts or self-harm, would be necessary to ensure chatbots could recognise such symptoms and respond appropriately; a process which is clinically difficult, ethically problematic and high-risk. Such deficiencies were evidenced by the launch of Woebot on Facebook, a chatbot designed to engage in therapy services via the platform.[65] Their automated system is designed to flag up serious situations and direct users to emergency services and helplines, however, criticisms that the app failed to respond appropriately to reports of child sexual abuse resulted in the Children's Commissioner for England deeming the app currently "not fit for purpose." [66]

3.1.3 Helping practitioners make better decisions

Operational pressures are an ongoing challenge for mental health services in the current context of staffing challenges and growing demand for services.[67] This is particularly a concern for mental health acute wards which, given the high threshold for admission, are high-risk environments.[68] As it stands, however, the Carter Review of efficiency in hospitals found half of trusts routinely go beyond planned staffing levels in order to meet the needs of patients.[69]

Data-driven technologies can be used in inpatient care to help providers better manage staffing levels in the context of these limited resources. For example, one NHS Trust is developing a tool to identify which inpatient wards are deemed high or low risk according to several factors to enable staff to be better allocated across the hospital and avert likely incidents. Further, as part of a wider initiative to improve collaboration across four mental health trusts in the West Midlands, the Mental Health Alliance for Excellence, Resilience Innovation and Training (MERIT) is working to formalise data sharing agreements between different trusts. This will allow bed managers to see more information about the availability of beds across the region, to tackle the current problem where "other hospitals may have available beds, but there is no visibility of this."[70]

In the clinical context, while automation of clinical decision-making is considered unlikely in the foreseeable future, there is significant potential for data-driven technologies to assist clinicians. Clinical Decision Support Systems (CDSSs) – electronic systems programmed to deliver recommendations based on data and scientific evidence – hold promise for helping clinicians make better informed decisions.[71] The tools, however, have had mixed success[72] and concerns have been raised regarding their ability to reflect the variety and complexity of patients' symptoms and the iterative nature of clinical decision-

64 Adam Miner, Arnold Milstein, and Jefferey Hancock, 'Talking to Machines about Personal Mental Health Problems', *JAMA* 318, no. 13 (2017).
65 Geoff White, 'Child Advice Chatbots Fail to Spot Sexual Abuse', *BBC News*, 11 December 2018.
66 Ibid.
67 Helen Gilburt, *Funding and Staffing of NHS Mental Health Providers: Still Waiting for Parity* (The King's Fund, 2018); Care Quality Commission, *The State of Care in Mental Health Services 2014 to 2017*, 15.
68 Care Quality Commission, *The State of Care in Mental Health Services 2014 to 2017*, 16.
69 Gilburt, *Funding and Staffing of NHS Mental Health Providers: Still Waiting for Parity*.
70 NHS, 'Our Vision', Webpage, MERIT, n.d.; Lis Evenstad, 'Sharing Health Data Is Vital to Patient Care, Says Mental Health CCIO', *Computer Weekly*, 22 June 2017.
71 Tom Foley and Fergus Fairmichael, *The Potential of Learning Healthcare Systems* (The Health Foundation, Newcastle University, Institute of Health & Society, 2015), 39.
72 Ibid.

making.[73] Yet CDSSs are progressively incorporating newer techniques, such as machine learning, and are therefore getting better at pooling and analysing larger and more complex patient data, evaluating the accuracy of predictions and learning from experience.[74]

These systems have not been extensively implemented in mental health clinical practice to date, although some examples exist. In the UK, the Galatean Risk and Safety Tool (GRiST) is a web-based decision support system designed to support practitioners assess and manage risks associated with metal health problems, including suicide, self-harm, self-neglect, vulnerability, and harm to others.[75] Developed by computer scientists at Aston University, GRiST integrates patients' anonymised records, clinicians' expertise and empirical evidence to create pre-programmed rules and decision trees to provide clinicians with a "risk estimate".[76] The system has been adopted by a small number of mental health trusts and, as of May 2018, held over 1.5 million completed individual risk assessments from 160,000 patients. In its current form, GRiST is a screening rather than a risk prediction tool. It can help trusts understand how clinicians make risk judgements, compare these judgments to the expert knowledge held within GRiST and feed these learnings back into the system. Trials have also shown that the system can help enrich the risk assessment process by flagging important behavioural "cues" that practitioners might have not considered incorporating into a risk assessment.[77]

CDSSs can also help promote the dissemination, uptake and continuous improvement of established clinical standards and practice guidelines. Clinicians often refer to standards and guidelines to inform their decisions. However, practical barriers, such as having to keep on top of an ever-growing body of information, have resulted in selective and piecemeal uptake.[78] By incorporating guidelines and standards into centralised intelligent systems, CDSSs can help streamline this process.[79] In the context of mental health, NICE guidelines set out recommendations for suitable services for people with a specific condition and are used to inform clinical practice. Translating existing guidelines and standards into computable form, such as NICE's guidelines, would allow evidence-based recommendations and medical knowledge to be incorporated into CDSS tools and ultimately, clinical workflows.[80] It would also make it possible to monitor compliance with guidelines in real-world settings. This might be particularly valuable in the mental health field where practitioners are often required to draw on various sources of data and information to design treatments. Guidelines within CDSSs could help deliver patient-specific guidance as well as helping to evaluate the efficacy of treatments retrospectively.[81] For example, if variation from the guidelines was shown to lead to better outcomes, protocols could be updated accordingly.[82] This would also create a feedback loop where clinicians could inform the guideline development process.

73 Casey C. Bennett and Thomas W. Doub, 'Expert Systems in Mental Health Care: AI Applications in Decision-Making and Consultation', in *Artificial Intelligence in Behavioral and Mental Health Care*, ed. David D. Luxton (San Diego: Academic Press, 2016).
74 Ibid.
75 CD Buckingham et al., 'Developing a Computer Decision Support System for Mental Health Risk Screening and Assessment', *Current Perspectives in Healthcare Computing*, 2004.
76 CD Buckingham and A Adams, 'The Grist Web-Based Decision Support System for Mental-Health Risk Assessment and Management', 2011.
77 Nawal A Zaher and CD Buckingham, 'Moderating the Influence of Current Intention to Improve Suicide Risk Prediction' (AMIA annual symposium proceedings, American Medical Informatics Association, 2016).
78 Beth Kotze and Bilyana Brdaroska, 'Clinical Decision Support Systems in Psychiatry in the Information Age', *Australasian Psychiatry* 12, no. 4 (2004).
79 Bennett and Doub, 'Expert Systems in Mental Health Care: AI Applications in Decision-Making and Consultation', 45; John Fox et al., 'From Practice Guidelines to Clinical Decision Support: Closing the Loop', *Journal of the Royal Society of Medicine* 102, no. 11 (2009); Richard N Shiffman et al., 'Bridging the Guideline Implementation Gap: A Systematic, Document-Centered Approach to Guideline Implementation', *Journal of the American Medical Informatics Association* 11, no. 5 (2004).
80 Fox et al., 'From Practice Guidelines to Clinical Decision Support: Closing the Loop'.
81 David Lobach et al., 'Enabling Health Care Decision Making through Clinical Decision Support and Knowledge Management', *Evidence Report/Technology Assessment* 203, no. 203 (2012).
82 Sophie Castle-Clarke, *What Will New Technology Mean for the NHS and Its Patients? Four Big Technological Trends* (The Health Foundation, The Institute for Fiscal Studies, The King's Fund and The Nuffield Trust, 2018).

Recommendation 1

The National Institute for Care and Health Excellence should make guidelines and protocols machine-readable to inform Clinical Decision Support Systems used in mental healthcare. This would make the guidelines more accessible to frontline practitioners and enable the guidelines to be continuously improved in accordance with up-to-date clinical evidence.

3.2 The right support, at the right time

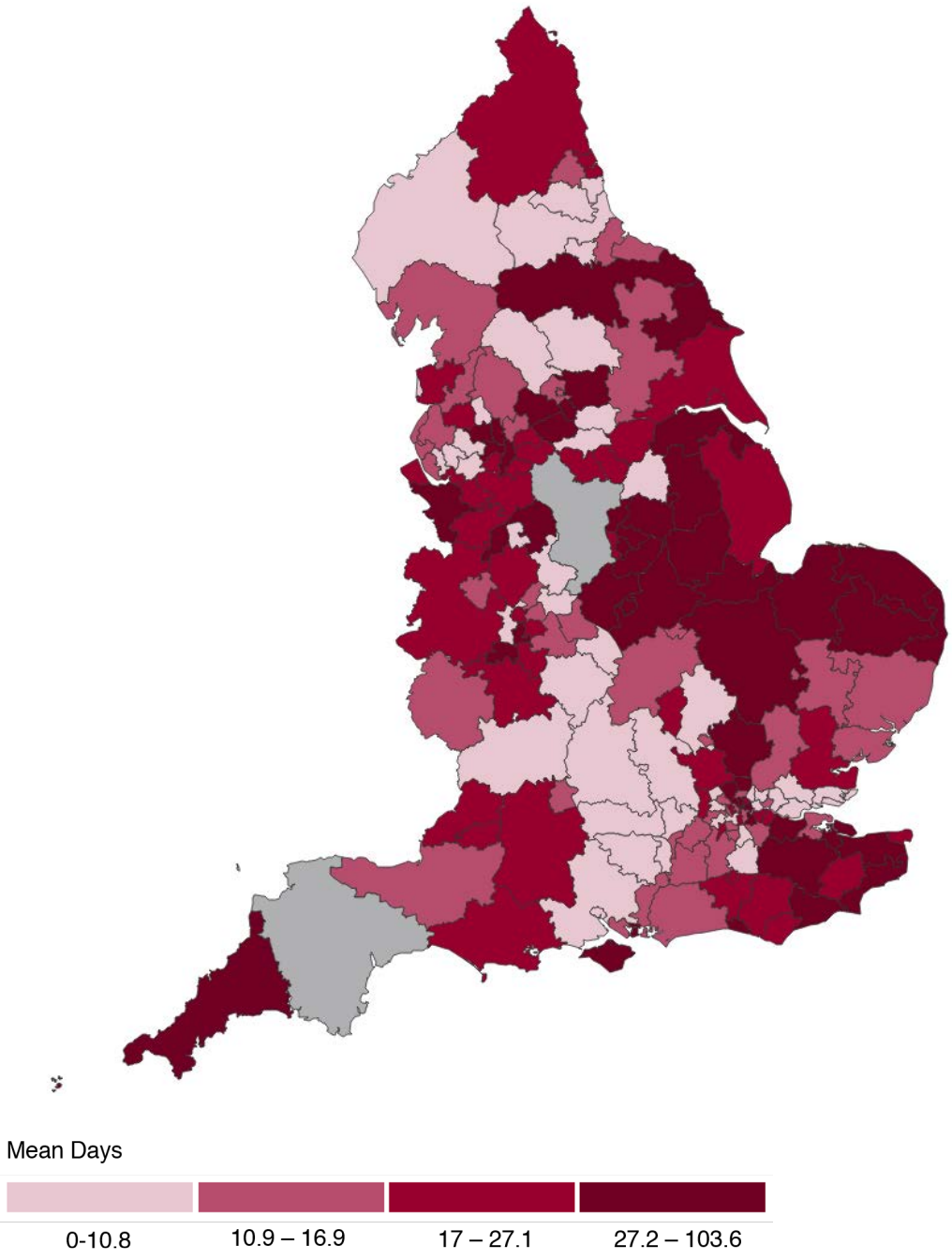
There is evidence to suggest that longer waiting times for treatment lead to poorer mental health outcomes.[83] However, most people experiencing mental health problems receive no treatment at all[84] and waiting times can be lengthy for those who do.[85] Data-driven technologies can help the NHS deliver more timely, appropriate interventions by providing insights into how people interact with services, helping patients and practitioners to spot early warning signs of mental health crises and opening-up alternatives to face-to-face support.

3.2.1 Bridging gaps in service provision

As a result of resource pressures, waiting times for psychological therapies are commonly too long for people suffering with symptoms of mental illness.[86] While IAPT services have vastly improved overall access to talking therapies – 88.9 per cent of referrals waited less than six weeks to enter treatment as of March 2019, above the target of 75 per cent – there are significant demographic and regional variations.[87] According to Public Health England's latest data release on IAPT services, there are marked differences in waiting times to enter IAPT treatment. The average waiting time to enter IAPT treatment was less than 10 days in 26 per cent of trusts in September 2018 but was over 31 days in 12 per cent of trusts. Figure 4 further exemplifies these variations in access. For instance, a patient living in the NHS Castle Point and Rochdale Clinical Commissioning Group (CCG) area waited an average of 2.6 days for an IAPT consultation, but for patients in the NHS Salford CCG area, this was 63.8 days.

83 A Reichert and R Jacobs, 'The Impact of Waiting Time on Patient Outcomes: Evidence from Early Intervention in Psychosis Services in England. – PubMed – NCBI', *Health Economics* 27, no. 11 (2016).
84 NHS England, The Five Year Forward View for Mental Health, 2016.
85 British Medical Association, Breaking down Barriers – the Challenge of Improving Mental Health Outcomes.
86 Ibid.
87 NHS Digital, 'Psychological Therapies: Reports on the Use of IAPT Services, England March 2019 Including Reports on the IAPT Pilots and Quarter 4 2018-19 Data', Webpage, NHS Digital, n.d.; Public Health England, 'Average Wait to Enter IAPT Treatment: Mean Wait for First Treatment (Days), September 2018', Webpage, Public Health Profiles, December 2018.

Figure 4: Regional variations in waiting times first IAPT treatment



Source: Public Health England, 'Average Wait to Enter IAPT Treatment: Mean Wait for First Treatment (Days), September 2018', Webpage, Public Health Profiles, December 2018.

In IAPT services, where there has been a strong focus on the collection of structured data from the outset, data-driven technologies can enable increased understanding of the disparities in access and quality of treatment. For example, in one study covering six IAPT services in South-West England, five themes – the waiting process, the relationship between IAPT services and GPs, expectations of assessment and treatment, rigidity of service and practitioner contributions to the relationship – were identified as contributing to patient disengagement and provide avenues for IAPT services to reduce non-attendance.[88] Data-generated insights can therefore help redesign services in ways that maximise long-term patient engagement in mental health services.

88 Dan Marshall et al., 'What IAPT Services Can Learn from Those Who Do Not Attend', *Journal of Mental Health* 25, no. 5 (2016).

In the context of secondary care, data-driven technologies can be used to bridge gaps in service provision. For many mental health conditions, symptoms can typically manifest outside of office hours, however, as it stands, even crisis teams are unable to deliver 24/7 access to care.[89] Run by Berkshire NHS Foundation Trust, the Sharon Network is an online support group designed to create an online peer community for people with eating disorders. It was developed in response to patients reporting a cliff-edge in support after discharge. The platform is monitored by senior clinicians, and concerning posts are flagged to these moderators through the monitoring of keys words. The model is yet to achieve genuine 24/7 support; currently, the app is only monitored during office hours and concerns about increased workload generated by it need further assessment. Nevertheless, the innovation has provided support to individuals where previously there was none.

Online support is also being developed to improve access to talking therapies. Ieso Digital Health is commissioned by over 40 NHS CCGs to deliver online cognitive behavioural therapy (CBT) to patients with common mental disorders, including anxiety, depression, phobias and stress-related symptoms. Patients are matched with a trained psychotherapist on a one-to-one basis in a secure online therapy room and courses are delivered in real-time using instant messaging. This service offers a flexibility that is not possible under face-to-face programmes, as it enables patients to access treatment outside of office hours. Other potential benefits include shorter waiting times and improved access for patients who are reluctant to contact services given the nature of their condition (for example agoraphobia), the perceived stigma associated with undertaking in-person therapy, as well as for those who cannot travel because of disability or geographical location.[90]

3.2.2 Averting crises

The importance of using data strategically to inform approaches to timely interventions in mental health has been underscored by researchers as well as practitioners.[91] With the appropriate safeguards in place, data-driven methods could help harness clinical datasets held within the NHS to spot warning signs of mental health crises before they arise and lead to more proactive care.[92]

For example, the use of risk stratification tools, which are specifically designed to identify those individuals who are at high risk of experiencing a future adverse event, are already in use across the NHS to identify which general practice patients are at highest risk of being admitted to hospital.[93] By doing so, these tools enable the NHS to offer these patients a proactive intervention to reduce their risk of experiencing an adverse event.[94] Similar technology is now being developed in the context of mental health, although much of this innovation is currently at the research stage (See Figure 5).[95]

89 Care Quality Commission, *Right Here Right Now* (Care Quality Commission, 2015).
90 Ieso Digital Health, 'Transforming Mental Health Care Using a Data-Driven and Evidence-Based Approach', Webpage, 2019; Ana Catarino et al., 'Demographic and Clinical Predictors of Response to Internet-Enabled Cognitive–Behavioural Therapy for Depression and Anxiety', *BJPsych Open* 4, no. 5 (2018).
91 Adam M Chekroud, 'Bigger Data, Harder Questions: Opportunities throughout Mental Health Care', *JAMA Psychiatry* 74, no. 12 (2017).
92 Sumithra Velupillai et al., 'Risk Assessment Tools and Data-Driven Approaches for Predicting and Preventing Suicidal Behavior', *Frontiers in Psychiatry* 10 (2019).
93 Operational Research and Evaluation Unit, NHS England, Risk Stratification: Learning and Impact Study (NHS, 2017).
94 Ibid., 2.
95 Taylor Burke, Brooke Ammerman, and Ross Jacobucci, 'The Use of Machine Learning in the Study of Suicidal and Non-Suicidal Self-Injurious Thoughts and Behaviors: A Systematic Review', *Journal of Affective Disorders* 245, no. 15 (2019); Colin Walsh and Jessica Ribeiro, 'Predicting Risk of Suicide Attempts Over Time Through Machine Learning', *Clinical Psychological Science* 5, no. 3 (2017).

Figure 5: Using risk stratification models to identify and avert mental health crises

Led by Birmingham and Solihull Mental Health NHS Foundation Trust, the RAIDplus Testbed[96] is developing a predictive algorithm to apply risk stratification to mental health by building models that predict the likelihood of being admitted to a psychiatric hospital. It combines four years of historical clinical and sociodemographic data to provide an overall indication of a patient's risk of experiencing a mental health crisis. Data will be drawn from a wider range of sources, going beyond typical patients' characteristics such as age, diagnosis and previous hospital admissions.

The goal is 'smarter triage' which proactively directs people to services most appropriate to their needs straight away.

However, as a majority of interviewees have noted, predicting when a crisis will occur, or exactly when symptoms will worsen, is a challenge given the complexity and unpredictable nature of mental illness. Therefore, these tools are aimed as supportive mechanisms working within a broad framework of interventions and structures. They particularly lend themselves to more collaborative approaches to designing care which may be particularly relevant for long-term mental health conditions. These tools are not intended to replace current practice and are unlikely to be of benefit in isolation.

Real-time data collected from personal digital devices, such as screen time, call frequency, light sensors, geographical information and social media usage, could offer new ways to identify problems before people reach crisis point. Known as 'digital phenotyping', this could be a particularly important development in the context of mental health, as symptoms can be socially, as well as biologically, determined.[97] Unlike existing ways of monitoring symptoms overtime, these types of data can, with an individual's consent, be collected passively on a real-time basis, making it possible to see how symptoms vary across time, space and social contexts, while not creating an additional burden on the individual.[98] With four out of five UK adults now estimated to have a smartphone, the cost-efficiency and scalability of this technology could be significant. However, given the fact that people with lower socioeconomic status have a higher likelihood of developing and experiencing mental health problems, further research is needed to ensure data-driven tools do not widen inequalities in access to mental health services.[99]

Research is ongoing to explore the potential of data derived from wearable devices to develop more proactive approaches to mental health treatment.[100] In a pilot study in the United States, 17 participants with a diagnosis of schizophrenia used the Beiwe app on their smartphone for a period of three months to monitor mobility and social behaviour. Three participants relapsed during this period, and had collected sufficient data prior to relapse.[101] From this small sample size, researchers were able to identify "statistically significant anomalies" in the behaviour of service users "in the days prior to relapse"; the rate of anomalies detected in the fortnight prior to relapse was 71 per cent higher than the

96 Birmingham and Solihull Mental Health NHS Foundation Trust, 'Using Predictive Analytics to Prevent Mental Health Crisis', in *Advancing Applied Analytics: Round 1* (The Health Foundation, 2018).
97 Jukka-Pekka Onnela and Scott L Rauch, 'Harnessing Smartphone-Based Digital Phenotyping to Enhance Behavioral and Mental Health', *Neuropsychopharmacology* 41, no. 7 (2016).
98 Lampros C. Kourtis et al., 'Digital Biomarkers for Alzheimer's Disease: The Mobile/Wearable Devices Opportunity', Npj Digital Medicine 2, no. 1 (2019); Torous, Staples, and Onnela, 'Realizing the Potential of Mobile Mental Health: New Methods for New Data in Psychiatry'.
99 Deloitte, *Global Health Care Outlook: The Evolution of Smart Health Care*, 2018; Onnela and Rauch, 'Harnessing Smartphone-Based Digital Phenotyping to Enhance Behavioral and Mental Health'.
100 Mental Health Foundation, *Mental Health Statistics: Poverty* (Mental Health Foundation, 2019); World Health Organisation (WHO), 'WHO | About Social Determinants of Health', Webpage, WHO, 2019.
101 Ian Barnett et al., 'Relapse Prediction in Schizophrenia through Digital Phenotyping: A Pilot Study', *Neuropsychopharmacology* 43, no. 8 (2018); Paul Harrison, 'Adult Mental Health: Innovation in Diagnosis and Treatment', Webpage, Oxford Health Biomedical research Centre, 2019; Onnela Lab, 'Beiwe Research Platform', Harvard .H Chan School of Public Health, 2019; Cotton, *Using Digital Technology to Design and Deliver Better Mental Health Services: Perspectives from Australia and the USA*, sec. Digital Phenotyping; Colin Walsh and Jessica Ribeiro, 'Predicting Risk of Suicide Attempts Over Time Through Machine Learning'.

rate of anomalies during other time periods.[102] This could facilitate interventions before symptoms escalate, avoid individuals reaching crisis and potentially reduce overall costs of care.[103] Additionally, Remote Assessment of Disease and Relapse in Central Nervous System Disorders (RADAR-CNS) is an ongoing international research project which aims to develop new ways of monitoring depression using wearable and smartphone technology. It examines the potential to detect changes in behaviour, mood and sleep to predict, and possibly avoid, relapse.[104] It should be noted, however, that the clinical validity of 'digital phenotypes' is not yet well established and further research is required before these tools will be able to inform clinical practice.[105]

3.2.3 Facilitating self-management

Seventy-five per cent of people in England experiencing mental health problems receive no treatment at all.[106] Indeed, the NHS's own guidance advises that "some mental health problems can be managed without the help of a GP."[107] Digitally-delivered interventions can play an important role in enabling people to manage their own mental health better, both by allowing patients to monitor symptoms and reflect back on their feelings as well as to monitor personal triggers and warning signs. There are a range of mood-tracking apps available, such as Unmind, where users can log different factors associated with mental health, such as sleep and stress.[108] Many of these digital solutions enable people to collect and record information relevant to them and use it to set goals or develop a crisis plan. For instance, Calm Harm, an app designed to help people manage the urge to self-harm, includes a ''My Log" feature where people can record how strong the urge was, how they overcame it and why the urge happened in the first place.[109] Some of these solutions employ AI to establish one-to-one conversations with people. These tools, also referred to as 'conversational agents', are increasingly used to mimic therapeutic support, help patients self-manage their conditions and provide them with information and educational resources.[110]

It must be noted, however, that in the same way that face-to-face therapy is not suitable for everyone, neither will digitally delivered therapy. More research is needed to understand which groups are most likely to use these services, and whether or not digital therapies are expanding access to mental health services.

As noted by several interviewees, "clinicians repeat themselves a lot" and self-management tools could ease pressure on clinicians by automating general information and advice. The NHS's own online mental health advice service, Moodzone, has been developed to provide generalised tips and advice to the general population, and includes a directory of approved mental health apps and tools.[111] These preventative measures may help those who do not have a clinical diagnosis but nevertheless are experiencing symptoms with low-level needs, and free up in-person services for those in greatest need.

102 Barnett et al., 'Relapse Prediction in Schizophrenia through Digital Phenotyping: A Pilot Study'.
103 Ibid., 1663.
104 Innovative Medicines Initiative, 'Radar-CNS', 2019.
105 Foley and Fairmichael, *The Potential of Learning Healthcare Systems*.
106 NHS England, *The Five Year Forward View for Mental Health*.
107 NHS, 'How to Access Mental Health Services', NHS, 2019.
108 NHS, 'NHS Apps Library'.
109 Calm Harm, 'About Calm Harm'.
110 Kyo-Joong Oh et al., 'A Chatbot for Psychiatric Counseling in Mental Healthcare Service Based on Emotional Dialogue Analysis and Sentence Generation', 2017; Miner, Milstein, and Hancock, 'Talking to Machines about Personal Mental Health Problems'; Adam Miner et al., *Conversational Agents and Mental Health: Theory-Informed Assessment of Language and Affect* (Stanford InfoLab., 2016).
111 NHS, 'NHS Apps Library'.

3.3 Moving towards prevention

Prevention has been outlined as a key objective in the NHS Long Term Plan.[112] Historically, mental health services have been largely reactive: in 2012, it was estimated that overall spending on the prevention of mental health problems represented less than 0.1 per cent of the total annual NHS mental health budget in England.[113]

By bringing together data from across biological, psychological and environmental sources, and facilitating new ways to analyse and interpret this information, data-driven technologies could enable researchers, mental health practitioners and patients to better understand and manage mental health conditions. This could also help improve the classification of diseases and offer insights into the factors determining how mental health conditions develop over the life course.

3.3.1 Understanding the causes

Because the underlying causes and mechanisms of mental health are not fully understood, true prevention remains a challenge. For example, primary prevention "is currently not possible" for conditions such as schizophrenia because its precise causes are unknown.[114]

Instead, the current criteria for diagnosing mental disorders is one in which mental illnesses are typically clustered by symptoms, rather than by psychosocial or biological indicators.[115] By enabling the consolidation of data from across a wide variety of sources, data-driven technologies provide opportunities to better describe the manifestations of a mental condition, in order to understand its underlying mechanisms. For example, The Alan Turing Institute is using machine learning techniques to develop robust modelling tools for predicting patients' risk of developing diseases such as dementia, anxiety and depression.[116] Using EHRs from individuals not showing symptoms of disease, coupled with genomic data and machine learning tools, the project seeks to isolate the biological, cognitive and environmental factors that affect disease progression over a lifetime.[117] In turn, this could lead to opportunities to improve diagnostic classifications, identify modifiable risk-factors and help the NHS better understand the likelihood of disease resilience and risk within different populations.[118] In the long-term, it could enable earlier diagnosis and more personalised treatment that transcends traditional classifications of mental illness/disorder.

As shown in Figure 6, research is underway to understand how digital phenotyping can be used to better characterise mental health conditions.[119] In order to support their wider deployment, a strong evidence base must be developed. There is also the need for robust privacy and governance frameworks to be in place to ensure the privacy of individuals is safeguarded, as discussed in Chapter 4.

112 NHS England, *NHS Long Term Plan*, 2019.
113 British Medical Association, *Breaking down Barriers – the Challenge of Improving Mental Health Outcomes*, 6.
114 Ibid.
115 Michael B First and Jerome C Wakefield, 'Diagnostic Criteria as Dysfunction Indicators: Bridging the Chasm between the Definition of Mental Disorder and Diagnostic Criteria for Specific Disorders', *The Canadian Journal of Psychiatry* 58, no. 12 (2013).
116 Danilo Bzdok and Andreas Meyer-Lindenberg, 'Machine Learning for Precision Psychiatry: Opportunities and Challenges', *Biological Psychiatry: Cognitive Neuroscience and Neuroimaging* 3, no. 3 (2018).
117 Ibid.
118 Ibid.
119 Onnela and Rauch, 'Harnessing Smartphone-Based Digital Phenotyping to Enhance Behavioral and Mental Health'.

Figure 6: Using digital biomarkers to predict Alzheimer's disease

Diagnosis quality in Alzheimer's disease is typically poor, with existing tests unable to detect disease at the earliest stages. This leads to difficulty when attempting to slow the progression of disease or helping people manage its potential behavioural and psychological symptoms. However, there is a growing body of evidence indicating that cognitive, sensory and motor changes may precede clinical manifestations of Alzheimer's disease by several years. There is now growing interest in the ability to monitor these changes using techniques such as eye movement tracking, fine motor movement and balance monitoring through smartphones and wearables, to facilitate early detection and diagnosis.[120] Mobile and wearable device-derived data could dramatically increase the number of people screened at a clinically asymptomatic stage; this is important because early detection presents a much lower burden on the health system compared to existing techniques, such as MRI scans.[121]

3.3.2 Improving outcome measures

In order to understand whether a specific treatment has been effective, access to reliable and relevant measures for monitoring outcomes is crucial. Yet, in mental health research, the development of measures has lagged behind other areas of medicine.[122] Indeed, the lack of clear-cut biomarkers for mental disorders means, in the absence of objective tests such as blood tests or X-rays, monitoring the effectiveness of mental health interventions over time presents specific challenges.

The current standardised measures used by NHS trusts to track mental health outcomes, the Health of the Nation Outcome Scales (HoNOS), have been criticised as bureaucratic and unhelpful for clinicians to perform their role.[123] The quality of the data is uncertain[124] and there has been criticism that HoNOS and other outcome measures used in mental health fail to reflect outcomes that are meaningful to patients.[125]

Data-driven technologies could help fill some of these gaps and offer ways to develop outcome measures that matter most to patients. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are valuable for assessing the effectiveness of treatments and evaluating services.[126] PROMs and PREMs are often administered as questionnaires that patients complete during their consultation. Whilst these tools have proven effective for informing mental health diagnoses,[127] their take-up in mental health practice has been limited.[128] A data-driven approach could help define which PROMs and PREMs are most effective and should be incorporated in interventions, for instance in mental health apps.[129] Tools could then be developed to assist practitioners in collecting PROMs and PREMs in more systematic ways. Examples of such platforms already exist elsewhere to help practitioners access validated PROMs questionnaires and

120 Lampros Kourtis et al., 'Digital Biomarkers for Alzheimer's Disease: The Mobile/Wearable Devices Opportunity', *Digital Medicine*, n.d.; Jeremiah KH Lim et al., 'The Eye as a Biomarker for Alzheimer's Disease', *Frontiers in Neuroscience* 10 (2016).
121 Lampros Kourtis et al., 'Digital Biomarkers for Alzheimer's Disease: The Mobile/Wearable Devices Opportunity'; Michael Gold et al., 'Digital Technologies as Biomarkers, Clinical Outcomes Assessment, and Recruitment Tools in Alzheimer's Disease Clinical Trials', *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 4 (24 May 2018).
122 Amy M Kilbourne et al., 'Measuring and Improving the Quality of Mental Health Care: A Global Perspective', *World Psychiatry* 17, no. 1 (2018).
123 Ride Jemimah and Rowena Jacobs, *Clinical Engagement with HoNOS* (Centre for Health Economics, University of York, 2018), 27.
124 Ibid., 13.
125 Mike J. Crawford et al., 'Selecting Outcome Measures in Mental Health: The Views of Service Users', *Journal of Mental Health (Abingdon, England)* 20, no. 4 (2011).
126 Jenna Jacob et al., 'Measuring What Matters to Patients: Using Goal Content to Inform Measure Choice and Development', *Clinical Child Psychology and Psychiatry* 22, no. 2 (2017).
127 Susan Marshall, Kirstie Haywood, and Ray Fitzpatrick, 'Impact of Patient-reported Outcome Measures on Routine Practice: A Structured Review', *Journal of Evaluation in Clinical Practice* 12, no. 5 (2006).
128 Ibid.
129 Simon Leigh, 'Comparing Apples and Oranges: Barriers to Evidence-Based Practice for App-Based Psychological Interventions', *Evidence-Based Mental Health* 19, no. 3 (2016).

create personalised patient questions.[130] Efforts are also being made to benchmark outcomes measurement tools to help commissioners procure solutions that are validated and compliant with data access, security and reliability requirements. For instance, the International Consortium for Mental Health Outcomes (ICHOM) has launched ICHOM TechHub, a review-based database of apps and platforms which collect PROMs.[131]

Data-driven technologies could help improve the quality of the outcomes data being collected by making data collection less onerous for practitioners and enabling real-time data capture. It could also help determine which of the available treatments are most effective, and for which patient cohorts, by bringing together information about patients from multiple sources, including their medical history and genome.[132]

130 Open Health Hub, 'Patient Reported Outcome Measures (PROM) with Improve', Webpage, 2019.
131 International Consortium for Health Outcomes Measurement, 'Announcing the ICHOM TechHub', Webpage, ICHOM, 2016.
132 Castle-Clarke, *What Will New Technology Mean for the NHS and Its Patients? Four Big Technological Trends*, 14.

4
Building a trustworthy system

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Data-driven technologies rely on collecting and processing health data about patients, and therefore need public support and appropriate governance to realise their potential.[133] If patients do not trust the technology being used, they will fail to engage with it, or might engage in deceptive behaviour by disclosing partial or inaccurate information. In turn, "if providers are unable to trust information coming from technologies, they are unlikely to find these technologies useful for their clinical practice."[134]

4.1 Understanding patient expectations

While several interviewees for this paper believed that treating mental health data as particularly sensitive only serves to reinforce the lack of parity of esteem between physical and mental health,[135] others argued that heightened concerns around confidentiality must be acknowledged.[136] Irresponsible handling of personal data about patients might exacerbate the stigma faced by people with mental illness, for instance if data were to be accessed by employers or credit agencies.[137] Because of the sensitive nature of mental health data[138] and the risks of it being misused, patients might be particularly wary about sharing such information.

Willingness to share mental health data by patients depends to how data are used and by whom. Studies show that patients are more willing to share data for research purposes, and with public health authorities, rather than with commercial organisations.[139] Patients are also more likely to share their mental health data when meaningfully engaged in decisions about the types of data being gathered and shared, the purposes for sharing and the benefits it might bring either to patients themselves or the wider society.[140]

The Clinical Record Interactive Search System (CRIS) developed by South London and Maudsley NHS Foundation Trust (SLaM) allows researchers to access anonymised information (see Glossary) from SLaM's electronic clinical records system and is often cited as a good-practice case study of how to meaningfully engage patients in the design of data-driven innovations. This has included extensive consultation on consent and opt-out models, the creation of patient-generated information models and leaflets, and the establishment of a patient-chaired oversight committee which reviews and approves all projects using data linked to CRIS.[141] Whilst not a formal framework for patient engagement in mental health data-related research, an interviewee for this paper highlighted that the CRIS model of governance is being adopted by other NHS trusts. Yet, the lack of clear implementation guidelines means that these trusts are often uncertain of how to operationalise the model and might end up spending extra resources.

Coproduction is not only important to foster patient trust in data-driven innovations – but is also crucial to ensure these innovations are useful and scalable, as patients, carers and staff play a crucial role in determining the adoption, sustainability and spread of health and

133 National Institute for Health and Care Excellence, *Data Science for Health and Care Excellence*, 2016.
134 Schueller, Washburn, and Price, 'Exploring Mental Health Providers' Interest in Using Web and Mobile-Based Tools in Their Practices'.
135 Evenstad, 'Sharing Health Data Is Vital to Patient Care, Says Mental Health CCIO'.
136 James Reed, 'Is the NHS Reinforcing Mental Health Stigma through Excessive Data Secrecy?', Webpage, Digital Health, 12 April 2018.
137 Donald J. Willison et al., 'Consent for Use of Personal Information for Health Research: Do People with Potentially Stigmatizing Health Conditions and the General Public Differ in Their Opinions?', *BMC Medical Ethics* 10, no. 1 (2009): 10; Elissa R Weitzman et al., 'Willingness to Share Personal Health Record Data for Care Improvement and Public Health: A Survey of Experienced Personal Health Record Users', *BMC Medical Informatics and Decision Making* 12 (2012): 39–39; Scott Monteith and Tasha Glenn, 'Automated Decision-Making and Big Data: Concerns for People With Mental Illness', *Current Psychiatry Reports* 18, no. 12 (2016).
138 Sarah Castell, Louise Robinson, and Heather Ashford, *Future Data Driven Technologies and the Implications for Use of Patient Data: Report on Public Dialogue* (Ipsos Mori, 2018); Wellcome Trust, *Summary Report of Qualitative Research into Public Attitudes to Personal Data and Linking Personal Data*, 2013.
139 Weitzman et al., 'Willingness to Share Personal Health Record Data for Care Improvement and Public Health: A Survey of Experienced Personal Health Record Users'.
140 Felicity Callard et al., 'Developing a New Model for Patient Recruitment in Mental Health Services: A Cohort Study Using Electronic Health Records', *BMJ Open* 4, no. 12 (2014).
141 Gayan Perera et al., 'Cohort Profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register: Current Status and Recent Enhancement of an Electronic Mental Health Record-Derived Data Resource', *BMJ Open* 6, no. 3 (2016).

care technologies (see Figure 9).[142] Several interviewees argued that meaningfully involving users in the development of new interventions is particularly important in mental health given that many treatments, such as talking therapies, must be 'done with', rather than 'done to', individuals.

Recommendation 2

The Royal College of Psychiatrists, in partnership with the Medicines and Healthcare products Regulatory Agency, should offer short, online training to mental health practitioners, and better publicise existing information about the Medicines and Healthcare products Regulatory Agency's Yellow Card Scheme. This will increase awareness among practitioners about how the Scheme can be used to identify and report issues with medical software, including certified mental health apps.

4.2 Obtaining consent

The use of data for research or product and service development of data-driven technologies requires careful consideration of the potential need to obtain consent, especially if this involves the processing of sensitive data.[143] In mental health, informed consent is contingent on an individual's mental capacity. Depending on the severity of a mental disorder, patients might not be able to weigh risks and benefits of a treatment or clinical trial, or clearly understand available alternatives. As technology in mental healthcare advances, developing a greater "understanding of capacity and informed consent" will become essential.[144] For instance, direct-to-consumer tools, such as mental health apps and wearable devices, might result in the collection of greater and more granular data about patients' behaviours without them being aware of the data being collected and how it is being used.[145] This might lead to patients disclosing information they would not otherwise consent to if they knew this information would be recorded. In traditional mental health practice, for example, practitioner-patient interactions are not recorded unless explicitly agreed to by the patient.[146] Patients might mistakenly assume that these standards are upheld for all services, including those delivered digitally. Dynamic consent models,[147] whereby patient consent is obtained at different points in time and on a case-by-case basis, could be used to improve transparency and build trust. Operationalising these models in practice might prove challenging.

Recommendation 3

The National Data Guardian should issue guidance for innovators and providers to improve the informed consent process for apps and other patient-facing mental health tools. This guidance should consider the needs of the different user groups accessing mental health services, such as children and young people, older people, and those with high levels of vulnerability.

142 Trisha Greenhalgh et al., 'Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies', *Journal of Medical Internet Research* 19, no. 11 (2017).
143 Information Commissioner's Office (ICO), 'Consent', Webpage, 2019.
144 Foley and Woollard, *The Digital Future of Mental Healthcare and Its Workforce: A Report on a Mental Health Stakeholder Engagement to Inform the Topol Review*, 27.
145 David D. Luxton, *Recommendations for the Ethical Use and Design of Artificial Intelligent Care Providers*, vol. 62, 2014.
146 Ibid.
147 Jane Kaye et al., 'Dynamic Consent: A Patient Interface for Twenty-First Century Research Networks', *European Journal of Human Genetics* 23, no. 2 (2015).

However, re-consenting is often costly and time consuming,[148] and can be particularly difficult in mental health research where patients show higher levels of disengagement with research programmes. Where these models prove impractical, alternative methods for enhancing the consent process should be considered. Examples exist both in medical practice and research, including the use of interactive screens, bullet point summaries of risks and benefits, videos, and simplifying the language used in terms and conditions and user agreements.[149] Tiered approaches, where patients select tiered opt-out options can also prove effective in giving patients a greater choice about sharing their data.[150] These methods should be explored and further developed, especially in cases where patients might lack guidance from a practitioner or carer.

There is also room for improvement in the processes governing the way researchers are granted access to mental health data. There is already a robust data request process in place to access information held by NHS Digital and this has been strengthened in recent years, although it should be noted that much information held by the NHS is held outside of NHS Digital.[151] The Independent Group Advising on the Release of Data (IGARD) was established in 2017 and is made up of independent specialists and lay members who review applications for sensitive data for research purposes.[152] The decisions made by IGARD are reached on balance of professional opinion, and interviewees have suggested that the process could become more streamlined through the development of a 'risk score' that estimates the risks of releasing data.

4.3 Engaging with practitioners

Realising the potential of data-driven technologies in healthcare requires ongoing and meaningful engagement with practitioners and professionals.[153] A consistent message emerging from interviews for this paper was that the adoption of new data-driven technologies depends on practitioners having evidence of the clinical effectiveness of the technology, as well as an understanding of the potential risks it could pose to patients.

Another factor affecting practitioner buy-in relate to concerns over liability and clinical responsibility if technologies fail. Mental health practitioners interviewed for this paper stressed the importance of safeguarding patients and ensuring data-driven technologies were safe and equitable. In particular, the lack of clear guidelines for information governance to support the implementation of data-driven tools in mental healthcare, remains a barrier for wider adoption.[154] Efforts are being made to address this. For example, practitioners interviewed for this paper praised the robustness of the NHS Apps Library review process, which requires developers to show evidence that their products meet standards in areas such as clinical safety, data protection, security and usability, and how anyone using them could see benefits to their health and wellbeing.[155]

Further, the Medicines Healthcare Products Regulatory Agency (MHRA) has produced guidelines[156] and the National Institute for Health and Care Excellence (NICE) an evidence framework[157] to help providers and practitioners assess the regulatory compliance and evidence requirements for digital health technologies. However, greater effort is needed to

148 Ibid.
149 National Institute of Mental Health, *Opportunities and Challenges of Developing Information Technologies on Behavioral and Social Science Clinical Research*, n.d.
150 Elizabeth A Bell, Lucila Ohno-Machado, and M Adela Grando, 'Sharing My Health Data: A Survey of Data Sharing Preferences of Healthy Individuals' (AMIA Annual Symposium Proceedings, American Medical Informatics Association, 2014).
151 Medical Research Council and NHS Digital, *Obtaining Data from NHS Digital for Health Research – a Guide for Researchers* (Medical Research Council, 2017), 3.
152 NHS Digital, 'Independent Group Advising on the Release of Data', Webpage, NHS Digital, 2019.
153 The AHSN Network, Department of Health and Social Care, and NHS England, *Accelerating Artificial Intelligence in Health and Care: Results from a State of the Nation Survey*, 2018, 39.
154 Eric Topol, The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. An Independent Report on Behalf of the Secretary of State for Health and Social Care (Health Education England, 2019), 11.
155 NHS, 'How We Assess Apps – NHS', Webpage, 2019.
156 Medicines and Healthcare Products Regulatory Agency, *Medical Device Stand-Alone Software Including Apps (Including IVDMDs)*, 2018.
157 National Institute for Health and Care Excellence, *Evidence Standards Framework for Digital Health Technologies*.

ensure these frameworks guide decisions on the ground. For instance, MHRA's Yellow Card Scheme[158] establishes a clear route for practitioners and patients to feedback on the safety of healthcare products. The scheme can now be employed to report potential side effects of medical software, including mental health apps. Experts interviewed for this paper warned that mental health practitioners were largely unaware of how the scheme operated for digital tools, and that more needed to be done to ensure it was effective in helping practitioners interrogate the safety and quality of these tools.

Recommendation 4

In order to build patient trust and encourage the responsible linkage of data to better understand mental health, the Royal College of Psychiatrists and NHS Digital, in partnership with Health Data Research UK, should develop a template for patient engagement for research initiatives linking mental health data. The patient engagement and governance models used by initiatives such as The Clinical Record Interactive Search System research programme could provide the basis for this framework.

Special caution must also be exercised to ensure data-driven systems do not inadvertently replicate or amplify biases and create health disparities, which several interviewees expressed remains a key concern for practitioners. This is especially problematic in mental health as datasets might be unrepresentative and the categorisation of mental illnesses might become unreliable over time and between practitioners.[159] Errors and biases embedded in algorithms might also be particularly damaging for patients with mental illness, who already face stigma and discrimination.[160] Capacity must, therefore, be built for mental health practitioners to identify potential biases in systems and better inform future models. Equally, new skills will be needed to avoid 'automation bias', or the tendency of practitioners to trust the recommendations make by an automated system rather than their own professional judgment.[161]

Ensuring that data-driven technologies become integrated into mental health services, as well as part of service redesign, will require collaboration between patients, practitioners, regulators and guiding bodies so patients and mental health professionals become confident in using these solutions.[162] NHSX's mandate to reform existing technology procurement processes will introduce greater clarity on these issues, helping providers purchase technologies that are compliant with standards. Equally, the new medical devices regulation, coming into effect in 2020, will introduce more stringent compliance standards for medical software, including mental health apps.[163] This should provide patients and practitioners with greater reassurance and confidence in software tools identified as clinically safe and meeting the relevant regulatory requirements.

4.4 Protecting sensitive data

Creating a data ecosystem that is trustworthy must be underpinned by secure data access procedures. Achieving this will require careful considerations of risks to data privacy at every stage of the data lifecycle from collection or processing.

158 Medicines and Healthcare Products Regulatory Agency, 'Yellow Card', Webpage, 2019.
159 Eric Topol, The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. An Independent Report on Behalf of the Secretary of State for Health and Social Care (Health Education England, 2019), 11.
160 Monteith and Glenn, 'Automated Decision-Making and Big Data: Concerns for People With Mental Illness'.
161 Kathleen L Mosier and Linda J Skitka, *Human Decision Makers and Automated Decision Aids: Made for Each Other?* (Erlbaum, 2018), 6.
162 NHS, The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. An Independent Report on Behalf of the Secretary of State for Health and Social Care, 11.
163 'Introductory Guide to New Medical Device Regulations Launched', Press Release, GOV.UK, 29 August 2017.

4.4.1 Inferred data

Digital phenotyping (see Glossary) presents particular challenges for data protection. The types of inferences that can be made from these new types of data are vast, and range from predicting Alzheimer's disease from search engine interactions to estimating susceptibility to depression based on social media usage.[164] However, there is currently a lack of clarity around whether these types of data are considered personal healthcare data or 'inferred data' under data protection law – which refers to when data is used to make predictions around individuals or groups.[165] This is important because individuals' rights to rectify, delete, transfer or object to how inferred information is used may be "significantly curtailed" compared to other types of personal data.[166] Given that the evidence-base for digital phenotyping to make inferences about mental health is growing, there is a need to clarify this 'grey area' in current data protection law.[167]

4.4.2 Data linkage

Another area of concern is data linkage. In most cases, researchers do not have access to identifiable information and instead use pseudonymised datasets. This is a procedure by which personally identifiable information fields are replaced by artificial identifiers. However, while linking data has been identified as a fundamental step to improve mental healthcare, it can lead to increased risks of identification, despite the use of pseudonymised data. This is because with more information about a given individual, the more likely it becomes that a unique characteristic of theirs is revealed. When combined with background information, this could be used to identify an individual. One expert noted this challenge is particularly pertinent in relation to the Mental Health Services dataset (MHSDS), as it is a "massive" dataset which includes inpatient and outpatient data with event dates and diagnoses. In the longer term, this may be improved by NHS Digital's work to establish a new national data architecture by 2020, which aims to create a modular system where small groups of data can flow between organisations providing care, rather than being held in large datasets.[168]

More immediately, the new NHS Digital Data Processing Services platform will allow datasets to be accessed, by authorised use, within a secure, cloud-based Data Access Environment. This will avoid the need to disseminate the data, thus reducing the risk of it being misused or combined with other data sources to reidentify individual patients. Alongside ensuring the necessary legal protections are in place, technical means to protect privacy should also be considered. The field of privacy enhancing technologies (PETs) is rapidly evolving to overcome these threats and includes a wide range of technologies to enable the safer storage, sharing and linkage of data.[169]

164 Sandra Wachter and Mittelstadt Brent, 'A Right to Reasonable Inferences: Re-Thinking Data Protection Law in the Age of Big Data and AI', Columbia Business Law Review, 2019.
165 Ibid.
166 Information Commissioner's Office, *Big Data, Artificial Intelligence, Machine Learning and Data Protection*, 2017, 71.
167 Wachter and Brent, 'A Right to Reasonable Inferences: Re-Thinking Data Protection Law in the Age of Big Data and AI'.
168 NHS Digital, 'The Future of Data, Insights and Statistics', Webpage, NHS Digital, 17 December 2018.
169 The Royal Society, *Protecting Privacy in Practice: The Current Use, Development and Limits of Privacy Enhancing Technologies in Data Analysis* (The Royal Society, 2019), 11.

5
Getting the basics right

5.1 Capturing high-quality data 41
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The successful development and deployment of data-driven technologies depend on access to high-quality representative data. However, collecting, accessing and analysing data in the context of mental healthcare can pose significant challenges. This chapter will outline the key barriers facing the deployment of these technologies and recommend how to overcome them.

5.1 Capturing high-quality data

In mental health clinical practice, records of detailed, interpersonal observations and symptom-based assessments are often required over extended periods of time to assess and monitor a condition accurately.[170] As a result, mental health data collection can be particularly challenging.

5.1.1 For clinical practice

Mental health clinicians spend a high proportion of their time recording information, and several interviewees for this paper noted "form fatigue" when it came to the collection of mental health data.[171] One reason for this is that mental health practitioners do not always see the potential secondary uses (e.g. research into mental health or the development of a data-driven tool) of the data they are being asked to collect.[172]

Ensuring the data collected by frontline practitioners are fed back to them in actionable ways is crucial to ensure practitioners see the relevance of the data they are being asked to collect, and in turn improve data quality.[173] Public Health England's "FingerTips" platform provides a useful example for how closing this feedback loop can be done in practice. The interactive platform brings together a range of publicly accessible data, including mental health data, with the aim of improving access to information and supporting commissioning, planning and providing services locally. Continued efforts should be made to make data more accessible to practitioners through improved visualisations and more interactive interfaces.

In addition, the Care Quality Commission found essential clinical information collected for direct patient care is not easy to locate and communicated to relevant staff. Digitisation must be the first step to ensuring healthcare data can be easily accessed by patients and practitioners. GPs became fully digitised by the mid-2000s, but secondary care lags behind.[174] The problems resulting from this lack of digitisation mean that "staff sometimes have to work with a confusing combination of electronic systems and paper," which is squandering staff time and impacting patient treatment.[175] There are now renewed efforts to digitise secondary care, with the NHS Long Term Plan committing to "fully digitise" secondary care providers by 2024.[176]

170 Richard G Jackson et al., 'Natural Language Processing to Extract Symptoms of Severe Mental Illness from Clinical Text: The Clinical Record Interactive Search Comprehensive Data Extraction (CRIS-CODE) Project', *BMJ Open* 7, no. 1 (2017).
171 Care Quality Commission, *The State of Care in Mental Health Services 2014 to 2017*.
172 Department for Health, *A Framework for Mental Health Research*, 2017, 26; Jemimah and Jacobs, *Clinical Engagement with HoNOS*, 6.
173 Gareth Iacobucci, 'NHSX: Hancock Sets up New Policy Unit to Support Technology in NHS', *The BMJ*, 2019.
174 Robert M. Wachter, *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England* (Department of Health and Social Care, 2016), 3.
175 Care Quality Commission, *The State of Care in Mental Health Services 2014 to 2017*, 34.
176 NHS England, *The NHS Long Term Plan*, 92; British Medical Association, *Lost in Transit? Funding for Mental Health Services in England*, 2018; Stephanie Kanuch, Kristin Cassidy, Neal Dawson, Melanie Athey, Edna Fuentes-Casiano, and Martha Sajatovic. 'Recruiting and Retaining Individuals with Serious Mental Illness and Diabetes in Clinical Research: Lessons Learned from a Randomized, Controlled Trial'. Journal of Health Disparities Research and Practice 9, no. 3 (2016). Yifend Liu et al., *Recruitment and Retention Strategies in Mental Health Trials – a Systematic Review*, 2018.

Recommendation 5

The National Institute for Health and Care Excellence, in partnership with NHSX, should update procurement rules to ensure that healthcare technologies bought by the NHS are user-friendly and that data is presented in accessible ways to frontline staff. This would equip practitioners with actionable insights to improve direct patient care.

5.1.2 For research

The improvement of research on mental health has implications for how mental health conditions are treated and how services are provided. The wealth of data held by the NHS presents ways to improve the recruitment of participants for mental health trials, which is a current challenge.[177] Currently, researchers rely on engaging with clinicians to identify and approach patients who meet specific criteria, which is impractical and inefficient.

Several initiatives are already being developed to improve communication between people who are interested in participating in research and medical research teams looking for suitable participants. *Join Dementia Research* and the *Discover Health Research Register*, for example, are both registers of people who have consented to be contacted about research opportunities that are relevant to them.[178]

Interviewees have noted, however, that setting up such platforms within the NHS will require overcoming significant administrative and governance challenges. The Scottish Health Research Register (SHARE) provides an example of how this could be achieved in practice.[179] SHARE is a voluntary register of people interested in participating in health research and who agree to allow SHARE to use the coded data in their various NHS computer records to check whether they might be suitable for health research studies. When researchers want to carry out a healthcare or medical research study, they will approach the custodians of the Register to identify people that are suitable for their study – e.g. age, sex, location, condition. The custodians of the Register are then able to approach suitable registered participants to tell them about the work being undertaken and invite them to take part.

Recommendation 6

In order to improve understanding of mental health conditions, NHS Digital should develop a research repository using NHS data to help researchers securely identify suitable participants for mental health research studies and assess the feasibility of research projects at early stages. Similar governance frameworks to the Scottish Health Research Register should be employed.

Further, while there is much scope to link these large national datasets in order to better understand mental health conditions (discussed further in Section 5.4), few are 'research ready' (see Glossary). Indeed, only a minority of data held by the NHS are organised in neat or 'clean' datasets, and the process of curating data is a labour-intensive and time-consuming process.[180] For this reason, there is increasingly a move towards using a small number of highly curated datasets. For example, led by the Institute of Health Informatics at University College London, CALIBER is a research platform consisting of 'research ready' variables extracted from linked and anonymised NHS data under licence from the Clinical Practice Research Datalink (CPRD); similar datasets are also available from Manchester and Swansea universities – again using de-identified patient data.

177 Yifend Liu et al., *Recruitment and Retention Strategies in Mental Health Trials – a Systematic Review*, 2018.
178 Imperial College Health Partners, 'Discover: North West London's Health Research Register', Webpage, 2019; Department of Health and Social Care, 'Join Dementia Research', Webpage, 2019.
179 NHS Research Scotland, 'SHARE', Webpage, SHARE, 2019.
180 Eleonora Harwich and Rose Lasko-Skinner, *Making NHS Data Work for Everyone* (Reform, 2018), 14; Neil D. Lawrence, 'Data Readiness Levels', *ArXiv*, May 2017.

Recommendation 7

NHS Digital, the Health Research Authority and the Clinical Research Network in England should collaborate with academic institutions to develop curated, 'research ready' datasets. This would make it easier for researchers to analyse and generate insights from data held by NHS organisations to improve the understanding of mental health conditions.

5.2 Overcoming the challenges of unstructured data

While subjective information about people's symptoms is typical in mental health and represents a "vast and complex tapestry of clinical information", it poses challenges for turning that information into structured data.[181] Much of this information is held in the free text part of the EHR which cannot easily be analysed.[182] Efforts have been made to introduce structured instruments for recording symptoms, but this has "not so far proved feasible in routine clinical practice outside specialist services."[183] Aside from these challenges, there is also a wider debate about whether mental healthcare data should become more structured. For some, binary choice classifications (e.g. yes and no; or right and wrong), may not capture the nuances needed in the context of mental healthcare.

Solutions have been developed to analyse unstructured data at scale. CRIS provides authorised researchers access to anonymised information extracted from unstructured electronic medical records. Resulting from the approach South London and Maudsley NHS Foundation Trust have taken over many years, CRIS now provides a searchable database that, using natural language processing, can extract information held in free text. Researchers can now analyse large volumes of free text in order to identify patterns and trends, which previously would have required researchers to review all individual records and code them one-by-one.[184] While the system is currently used across a number of trusts in the south of England, efforts must now be made to ensure this system is more nationally representative given the social determinants of mental health.

5.3 Towards data interoperability and portability

The interoperability of systems in mental health services is problematic as "systems do not talk to one another."[185] For clinical staff, this means the same information has to be duplicated across different systems, increasing the risk of error and consuming valuable staff time. This lack of interoperability is also hampering practitioners' ability to use patient records to inform treatment, with examples of "crisis teams not being able to access records for patients taken to a health-based place of safety."[186]

Widespread interoperability will require the development and enforcement of standards. The mandated adoption of SNOMED CT, an international clinical terminology, by mental health systems and provider organisations is a welcome step in this regard. It will allow codes used to categorise information such as diagnoses to be standardised across the NHS.[187] The standards are already being used by certain healthtech providers. For instance, DiADeM, a dementia assessment app developed by the Yorkshire and Humber Clinical Network, uses SNOMED CT codes.[188] As part of its wider remit to reduce the fragmentation of technology across the NHS, a key responsibility of NHSX will be to mandate such internationally recognised standards.[189]

181 Jackson et al., 'Natural Language Processing to Extract Symptoms of Severe Mental Illness from Clinical Text: The Clinical Record Interactive Search Comprehensive Data Extraction (CRIS-CODE) Project'.
182 Ibid.
183 Ibid.
184 Andrew M. McIntosh et al., 'Data Science for Mental Health: A UK Perspective on a Global Challenge', *The Lancet Psychiatry* 3, no. 10 (2016).
185 Care Quality Commission, *The State of Care in Mental Health Services 2014 to 2017*, 9.
186 Ibid., 34.
187 NHS Digital, 'SNOMED CT Implementation in Mental Health', Webpage, NHS Digital, 10 January 2019.
188 Alzheimer's Society, 'DiADeM (Diagnosing Advanced Dementia Mandate)', Webpage, Alzheimer's Society, 2019.
189 Maxine Mackintosh, 'NHSX : The Who, What, When and Groovy', *Forbes*, 8 April 2019.

As new types of data collection become available through smartphones and wearables, ensuring this valuable information is interoperable with existing systems is important so that it can be used to inform treatment across the care pathway and does not add to practitioners' workloads. To address this question of integration, Berkshire Healthcare NHS Foundation Trust has developed a patient-facing app that is predicated on being able to communicate with EHRs. For instance, mood monitoring within the app is automatically fed into the EHR for a clinician to view at each consultation. This represents a significant step forward in the use of data-driven technologies in mental healthcare as it goes beyond using static data for research purposes, and towards using real-time data to inform clinical practice.

Platforms which collect patient data also need to ensure data portability to avoid being locked into one service provider. This enables individuals to move personal information between service providers, and avoid losing or having to re-input any information in the process of switching providers. For example, someone should be able to move mood tracking data held within a smartphone app between different service providers, and onto NHS systems. This is crucial given the commissioning of platforms to capture new types of data within the NHS happens at a local level, meaning different NHS Trusts are working with different developers. The recently adopted General Data Protection Regulation (GDPR) mandates data portability, but it is crucial this regulation is enforced effectively.

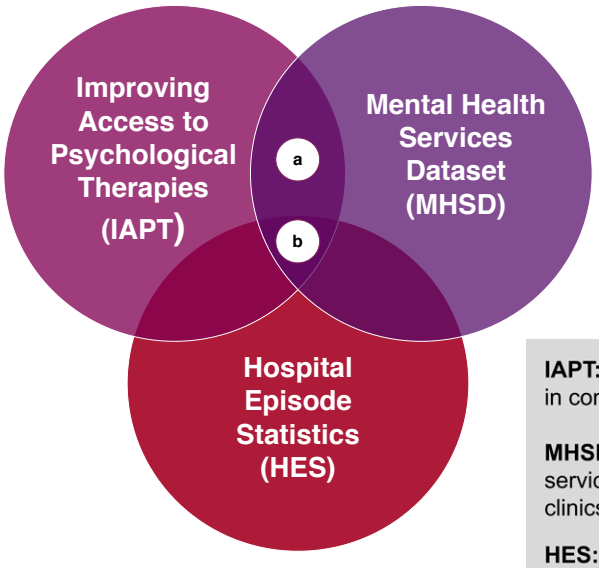
Recommendation 8

NHSX should require all healthtech providers to ensure interoperability and data portability by design. This would ensure that data generated from technologies such as wearables and sensors can be transferred across platforms.

5.4 Linking data across public services

The ability to link data from across the public sector for research purposes can provide a step-change in the way mental health issues are understood and treated. As discussed in Section 4.4, linking data is not only a question of whether it is technically possible, but it is mostly a question of whether the purpose of linking that data (temporarily or otherwise) is justified and whether privacy is safeguarded.

Figure 7: Data about mental health services held by NHS Digital



IAPT: dataset contains information about adults in contact with psychological therapy services

MHSDS: dataset includes information about services provided in hospitals and outpatient clinics

HES: dataset contains information about inpatients, outpatients and A&E attendance

Source: NHS Digital, *Reform* research.

Linking the IAPT, MHSD and HES datasets together (i.e. linkage b in Figure 7) would allow for more detailed monitoring of care pathways, and pinpoint ways to improve the service. There is a natural progression between the services recorded by these datasets. For example, in line with the stepped-care model for treating depression, a patient may enter low-intensity support through IAPT, and progress onto higher-intensity interventions provided by secondary mental health services.

Linking datasets can also be used to improve data quality by filling in information gaps. As shown in Figure 7, IAPT and HES are linked and MHSD and HES are linked, but linkages (a) and (b) have not yet been established, limiting the ability to understand continuity of care across NHS mental health services. There is a strong rationale to put the right safeguards in place to link these three main datasets, held by NHS Digital, recording clinical episodes.

Recommendation 9

NHS Digital should harness the potential of the significant volume of clinical data already held by the NHS by linking together the Mental Health Services Dataset, Improving Access to Psychological Therapies and Hospital Episode Statistics Dataset. Linking all three datasets would create greater visibility of patients' interactions with the healthcare system, which would allow for the better planning of services and a better understanding of patient outcomes.

In addition to making better use of the data that already exists within the health system, linkages with information outside healthcare may provide valuable insights into the wider determinants of mental health (see Figure 8). Linking datasets outside healthcare also presents opportunities to improve the quality of data for some socially excluded groups, such as those with substance use disorders, as information on these demographic groups is not consistently recorded in most vital registration and health information systems.[190]

190 Robert Aldridge et al., 'Morbidity and Mortality in Homeless Individuals, Prisoners, Sex Workers, and Individuals with Substance Use Disorders in High-Income Countries: A Systematic Review and Meta-Analysis', *The Lancet* 5, no. 10117 (2018).

Figure 8: Examples of datasets within and outside healthcare

Source: NHS Digital, *Reform* research. NB: This list is not exhaustive and does not include regional datasets.

However, linking datasets outside of healthcare can be technically challenging as finding ways to match individuals effectively from across datasets can be difficult in the absence of a unique identifier.[191] Other identifiers such as name, date of birth and postcode can be used to link datasets outside of healthcare but the availability of these identifiers varies between datasets. For example, homelessness data do not consistently contain such identifiers. Identifying the appropriate methods for data linkage is therefore complex, and interviewees argued this can be very time consuming. Greater transparency over approaches to data linkage would help spread best practice and support the development of valuable insights into mental health conditions.

Recommendation 10

To promote research that will deepen understanding of mental health conditions, NHS Digital should collaborate with bodies such as the Clinical Research Network in England to make approaches to data linkage more transparent by encouraging researchers to publish the code and methods used to link data in an open source platform. Guidance should be developed to ensure that data protection principles are preserved.

5.5 Scaling-up and sustaining change

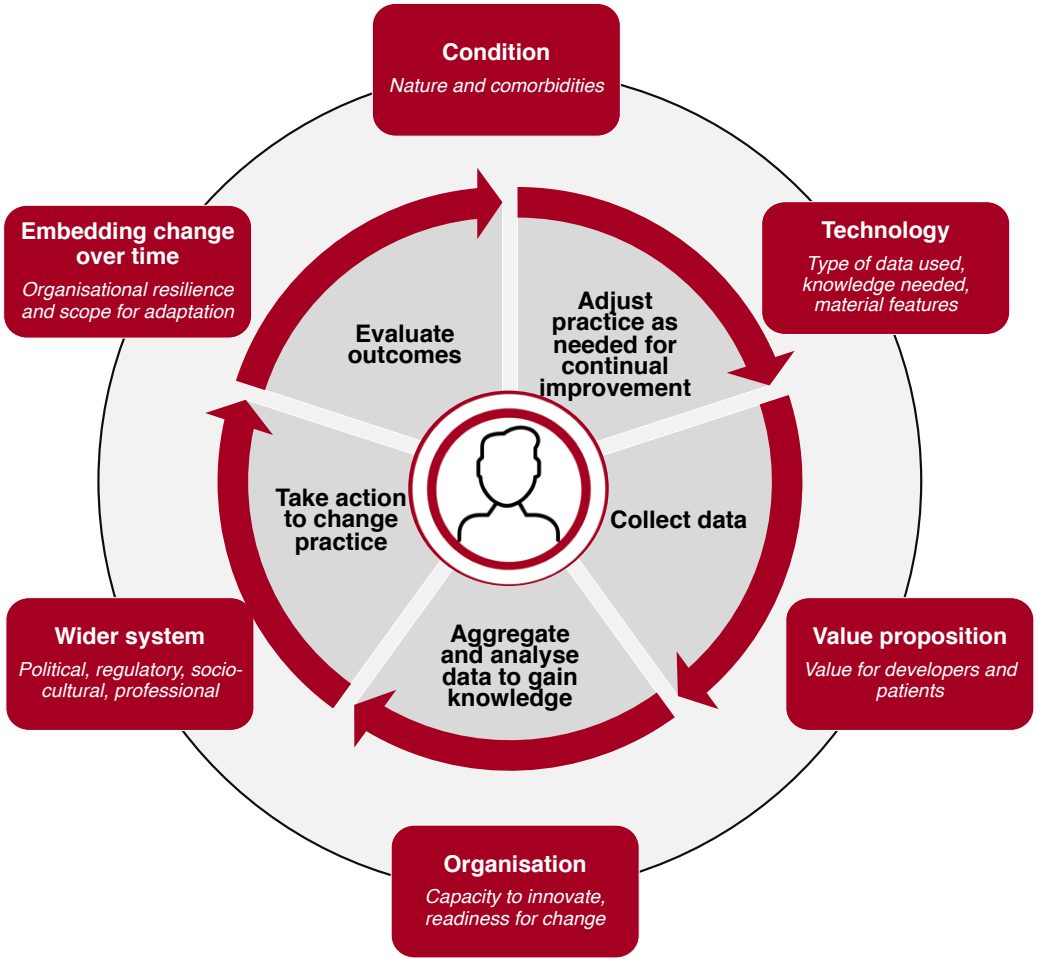
The adoption and spread of innovation is a problem across the NHS.[192] An important part of the solution is for the NHS to become a "learning healthcare system".[193] Such a system would create a cycle between assembling, analysing and interpreting data and feeding this back into clinical practice.[194] This is particularly pertinent in mental health as there are still significant gaps in understanding about what works well and in what contexts, given patients with the same diagnosis can experience different symptoms and respond very differently to treatments.

An important step towards achieving this is to ensure real-time data collected by patients can be used to inform care pathways. Applications of digital phenotyping have begun to address this. One such example is a patient-facing app called Mindstrong Health, which collects information about motor function and memory through swipes, taps and other touchscreen activities.[195] This patient-facing app is then joined-up with a clinician-facing app, creating opportunities for this new information to be used to inform care. A similar app known as ClinTouch also monitors patient physical activity, as well as geographical location and symptom data. These can be shared with relevant clinicians to support the patient with adherence to medication as well as to prevent relapse in adults with chronic and enduring severe mental illness.[196]

It must be recognised, however, that the adoption and scale-up of data-driven innovations in mental health depends on a plethora of other factors. Developed by Trish Greenlaugh et al. at the University of Oxford, the nonadoption, abandonment, scale-up, spread, and sustainability (NASSS) framework identifies seven domains which impact the spread of health technologies, including the condition or illness, the value to patients and developers, and an organisation's readiness for change (See Figure 9). This has been reflected in interviews for this paper; for example, one interviewee raised concern that while research conducted by academic institutions is well evidenced, there is currently little incentive for them to scale-up innovations after they have been trialled in one service.

191 Johnny M Downs et al., 'An Approach to Linking Education, Social Care and Electronic Health Records for Children and Young People in South London: A Linkage Study of Child and Adolescent Mental Health Service Data', *BMJ Open 9*, no. 1 (2019).
192 Ben Collins, 'Adoption and Spread of Innovation in the NHS', Webpage, The King's Fund, 16 January 2018.
193 Institute of Medicine, *The Learning Healthcare System: Workshop Summary*, 2007.
194 Foley and Fairmichael, The Potential of Learning Healthcare Systems.
195 Mindstrong, 'The Mindstrong Behavioural Healthcare Solution', Webpage, 2019.
196 Pauline Whelan et al., 'Mobile Early Detection and Connected Intervention to Coproduce Better Care in Severe Mental Illness', *Studies in Health Technology and Informatics* 216 (2015).

Figure 9: An ecosystem for sustainable and scalable healthcare innovation



Source: Adapted from T Greenhalgh et al., 'Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies', J *Med Internet Res* 19, no. 11 (2017); and Allen Flynn et al., 'The Knowledge Object Reference Ontology (KORO): A formalism to support management and sharing of computable biomedical knowledge for learning health systems', *Learning Health Systems* 2 (1 April 2018).

How to scale-up health technologies is a timely discussion given the NHS's commitment to spread best practice across the service. In 2017, NHS England named seven mental health Trusts – known as "Fast Followers" – to lead the second wave of digital transformation across NHS mental health services. These trusts will partner with the existing mental health global digital exemplars and learn from the "blueprints" they have developed.[197] In this process, consideration must be given to the unique organisational and cultural challenges present in each NHS trust.

Recommendation 11

To assess the feasibility of implementing and scaling-up digital innovations, the seven mental health trusts identified to lead the next wave of digital transformation across NHS mental health services should adopt the Non-adoption, Abandonment, Scale-up, Spread and Sustainability framework. Adopting this framework on this limited scale will also help build the evidence-base for its wider use across the NHS.

197 NHS England, 'Mental Health Global Digital Exemplars'.

Conclusion

Emerging data-driven technologies present great opportunities to help the NHS deliver transformation to mental health services. Capable of collecting, analysing and generating insights from multiple and increasingly complex sources of healthcare and patient-generated data, these tools are opening a "new frontier" in data collection and mental health support.[198]

Nevertheless, the deployment of data-driven tools within the NHS mental health services is still in its infancy and their impact and effectiveness is poorly understood. While recent years have seen increased interest in the use of consumer-facing tools, such as mental health apps, their adoption has been hampered by a lack of good quality evidence.

This paper shows that, in the short-term, the potential for these tools lies not in automating clinical tasks, but in giving time back to clinicians by streamlining repetitive tasks and freeing up time for them to spend with their patients. In the long-term, smart use of data might help clinicians better understand the biological causes of mental illness and support the creation of risk-stratification models and more comprehensive patient population profiles. Research is already underway exploring the application of predictive analytics on real-time, dynamic data to identify warning signs and triggers of a mental health illness before a crisis arises. This could create a paradigm shift in the way mental health conditions are diagnosed and treated; moving away from the traditional "diagnose-and-treat" model to a "predict-and-prevent" approach.

In order to support the adoption and spread of data-driven tools in mental health, building trust with patients, healthcare professionals and the public is crucial.[199] This will require developing high standards of transparency, data security and information governance. While co-production is already integral to the way mental health services are delivered, a national discussion is needed on the 'ground rules' governing the collection and sharing of data for mental health research.

One of the main barriers to the successful implementation of data-driven technologies in mental healthcare is the paucity of structured and accessible data. The NHS needs to move forward with the digitisation agenda, improving data interoperability and portability through the development and enforcement of open standards. Effort must also be directed at ensuring that data collected through data-driven tools, such as smartphones and wearables, are interoperable with existing systems, and that insights derived from these data are presented to practitioners in actionable ways. The opportunities brought about by linking data from healthcare and non-healthcare datasets for mental health research must be carefully considered. When data linkage is deemed appropriate, the NHS must collaborate with academia and national bodies to develop robust data linkage frameworks.

Finally, creating an ecosystem of sustainable and scalable healthcare innovation in mental health requires consideration of the multiplicity of factors impacting the long-term adoption of these tools. Frameworks such as the Non-adoption, Abandonment, Scale-up, Spread and Sustainability framework could prove useful in helping to assess the feasibility of data-driven initiatives and provide a blueprint for implementation. Doing this will help the NHS realise its ambitions to become "the most advanced health and care service in the world."[200]

198 National Institute of Mental Health, 'Technology and the Future of Mental Health Treatment', Webpage, 2019.
199 The AHSN Network, Department of Health and Social Care, and NHS England, *Accelerating Artificial Intelligence in Health and Care: Results from a State of the Nation Survey*.
200 GOV.UK, 'Matt Hancock: New Technology Is Key to Making NHS the World's Best'.

Appendix

On 4th December 2018, *Reform* held a research roundtable with 21 experts to determine the scope of the research project and discuss the ethical implications of implementing data-driven technologies in mental healthcare. The attendees were as follow:

Prof Kathryn Abel, National Institute for Health Research (NIHR) National Specialty Lead for Mental Health Clinical Research Network (CRN)

Heather Bolton, Head of Psychology, Unmind

Mathew Brown, Senior Portfolio Developer, Neuroscience and Mental Health, Wellcome Trust

Maria Buckland, Health and Public Service Consultant, Accenture

Dr Richard Caddis, Chief Medical Officer and Director Health, Safety & Wellbeing, BT Group

Simon Cartmell, Executive Chairman, Ieso Digital Health

Dr Joshua Chauvin, Partnerships Manager, Associate Fellow, Evidence-Based Practice Unit Mindstrong Health, University College London (UCL) (has since changed position)

Dr Becky Inkster, self-employed neuroscientist, Fellow Department of Psychiatry, University of Cambridge

Dr Thomas Insel, Co-Founder and President, Mindstrong Health

Dr Indra Joshi, Clinical Director, NHS England (has since changed position)

Sabrina Kamayah, Senior Policy Advisor, The British Psychological Society

Maxine Mackintosh, PhD student, Alan Turing Institute and University College London's Institute of Health Informatics; Co-founder One Health Tech

Dr Alex McKeown, Postdoctoral Research Fellow, Oxford University

Jessica Morley, Technology Adviser, Department of Health and Social Care (has since changed position)

Emma Thomas, Chief Executive, Young Minds

Dr Justin Varney, National Lead for Adult Health and Wellbeing, Public Health England

Dr Pauline Whelan, Co-Director CAMHS, Digital, University of Manchester and Greater Manchester Mental Health NHS Foundation Trust

Dr James Wollard, Digital Mental Health Lead, NHS Digital

Prof Miranda Wolpert, Director of Evidence Based Practice Unit, University College London (has since changed position)

Tina Woods, Founder and CEO, Collider Health

Dr Lisa Wright, Consultant Psychiatrist, Royal College of Psychiatrists

Glossary

Anonymised data: data that has been processed with the aim of irreversibly preventing the identification of the individual to whom it relates. Data can be considered effectively and sufficiently anonymised if it does not relate to an identified or identifiable natural person or where it has been rendered anonymous in such a manner that the data subject is not or no longer identifiable.[201]

Artificial intelligence: any manmade agent (i.e. computer programme or robot) that exhibits intelligence. Intelligence is defined as an "agent's ability to achieve goals in a wide range of environments."[202]

Automation bias: a specific class of errors people tend to make in highly automated decision-making contexts, when many decisions are handled by automated aids. In healthcare, automation bias is understood as professionals' propensity to favour suggestions from automated decision-making systems, instead of their clinical judgment.

Biomarker: characteristics (such as a physiologic, pathologic, or anatomic characteristic or measurement) that are objectively measured and evaluated as an indicator of normal biologic processes, pathologic processes, or biological responses to a therapeutic intervention.[203]

Care pathway: a way of setting out a process of best practice to be followed in the treatment of a patient or client with a particular condition or with particular needs.

Clinical Decision Support System: software designed to support clinical decision-making, in which the characteristics of an individual patient are matched to a computerised clinical knowledge base and patient-specific assessments or recommendations are then presented to the clinician or the patient for a decision.[204]

Co-morbid: the presence of more than one disorder or disease at the same time.

Conversational agent: software systems that receive and interpret human-language inputs, using mediums such as the internet, and respond to statements using ordinary natural language.[205]

Data-driven technology: technology based on the collection, analysis and interpretation of data. Data-driven technologies use data as part of its creation and not just or solely as part of its functioning, and therefore require access to large volumes of information and data to operate.[206]

Deindentified data: pseudonymised data except that the date of birth of the patient is removed. In addition, there is no way of knowing if a same person has, for example, received treatment several times as it appears as a single entry each time.

Digital phenotyping: real-time data collected from personal digital devices, such as screen time, call frequency, light sensors, geographical information and social media usage.

Dynamic consent: approach for engaging individuals about the use of their personal information. It is also an interactive personalised interface that allows participants to engage as much or as little as they choose and to alter their consent choices in real time.[207]

201 Information Commissioner's Office (ICO), 'What Is Personal Data?', Webpage, n.d.
202 Shane Legg and Marcus Hutter, 'A Collection of Definitions of Intelligence', *Frontiers in Artificial Intelligence and Applications* 157 (2007).
203 Andrea Coravos, Sean Khozin, and Kenneth D Mandl, 'Developing and Adopting Safe and Effective Digital Biomarkers to Improve Patient Outcomes', *NPJ Digital Medicine* 2, no. 1 (2019).
204 Ida Sim et al., 'Clinical Decision Support Systems for the Practice of Evidence-Based Medicine', *Journal of the American Medical Informatics Association* 8, no. 6 (2001).
205 Adam Miner et al., 'Conversational Agents and Mental Health: Theory-Informed Assessment of Language and Affect', 2016.
206 The Academy of Medical Sciences, *Our Data-Driven Future in Healthcare*.
207 Kaye et al., 'Dynamic Consent: A Patient Interface for Twenty-First Century Research Networks'.

Improving Access to Psychological Therapies: a programme that supports the frontline NHS in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suffering from depression and anxiety disorders in England. It was created to offer patients a realistic and routine first-line treatment, combined where appropriate with medication, which traditionally had been the only treatment available.

Learning Health System: a system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience.

Machine learning: a subset of AI that allows computer systems to learn by analysing huge amounts of data and drawing insights from it rather than following pre-programmed rules.[208]

Risk-stratification: tools which are specifically designed to identify those individuals who are at high risk of experiencing a future adverse event, such as a readmission within 30 days or an unplanned hospital admission in the next 12 months.[209]

Population data: "anonymised information grouped together so that it doesn't identify" individuals.[210]

Pseudonymised data: data "about individuals but with identifying details (such as name or NHS number) replaced with a unique code."[211]

Research-ready data: processed data which has been fully calibrated, combined and cleaned for research purposes.

208 The Economist Intelligence Unit, *Advanced Science and the Future of Government* (The Economist Group, 2016).
209 NHS England, *Next Steps for Risk Stratification in the NHS*, 2015.
210 NHS Digital, 'How We Look after Your Health and Care Information', Webpage, 2019.
211 Ibid.

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