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## Shared goals for mental health research: what, why and when for the 2020s

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### ABSTRACT

Mental health problems bring substantial individual, community and societal costs and the need for innovation to promote good mental health and to prevent and treat mental health problems has never been greater. However, we know that research findings can take up to 20 years to implement. One way to push the pace is to focus researchers and funders on shared, specific goals and targets. We describe a consultation process organised by the Department of Health and Social Care and convened by the Chief Medical Officer to consider high level goals for future research efforts and to begin to identify UK-specific targets to measure research impact. The process took account of new scientific methods and evidence, the UK context with a universal health care system (the NHS) and the embedded research support from the National Institute for Health Research Clinical Research Network, as well as the views of individual service users and service user organisations. The result of the consultation is a set of four overarching goals with the potential to be measured at intervals of three, five or ten years.

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### What is missing from an agenda for mental health research?

Mental health problems are the single largest contributor to disease burden in Europe with myriad consequences for individuals, communities, and society (Wittchen et al., 2011). Reports of increased mental health problems in the pandemic put a spotlight not only on these difficulties (Brooks et al., 2020; Office for National Statistics, 2020; Pfefferbaum & North, 2020; Pierce et al., 2020; Taquet et al., 2020), but also on the research we need to carry out, and implications for the future organisation of mental health services (Holmes et al., 2020; Moreno et al., 2020; O'Connor et al., 2020). Expert reviews are helpful in highlighting what we know and where there are gaps, but we are missing a crucial element – where are we heading? Without clear targets and goals for mental health we will be amassing information without any clear trajectory, or worse, no clear understanding of achievements or the expected timescale.

### What sort of goals?

Some people thrive despite being affected by mental health difficulties, but many more may have their life chances

curtailed. For example, children and young people have diminished educational opportunities if they have poor mental health (Thomas & Morris, 2003; Wickersham et al., 2021; Wittchen et al., 2000). We now also have evidence that childhood mental health difficulties are associated with later economic adversity, most noticeably in lower earnings (Evensen et al., 2017). Unemployment is common in those who have mental health difficulties, exacerbated by discrimination against employing individuals with mental health problems who want to work (Thomas & Morris, 2003). Social relationships can also suffer, often resulting in poorer quality relationships, both within families and in friendship groups, which erodes social support and leads to loneliness (e.g. Lim et al., 2020; Wittchen et al., 2000). When a person in the family has a mental health problem this also has an impact on the health and wellbeing of all family members. Finally, there is the economic consequence. This includes not only the costs of supportive services in health and social care, but also to the economy from lost employment in the individual and supportive family members. Notably, days off sick have increased by 24% because of stress, depression and anxiety, and conservative estimates of the number of days lost because of “serious mental illness” has doubled from 2009 to 2013 (Davies, 2014; Department for Work &

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Pension, 2014; Office for National Statistics, 2014) and more recent data shows similar effects (Dorrington et al., 2020). These figures come from routinely collected data and are likely to be an under-estimate. Indeed, the most recent estimate of the economic burden is 4.1% of Gross Domestic Product (Organization for Economic Co-operation & Development, 2018). Poor outcomes that need to change therefore cover the broad areas of education, social relationships, employment, and financial effects and each of these affect social integration and limit personal goals. The pandemic will have made matters worse with the economic downturn and employment prospects looking bleak, a situation known to exacerbate mental health difficulties (Nordt et al., 2015; O'Connor et al., 2020; Office for National Statistics, 2020; Wykes et al., 2015).

### Why now?

It is well-known that at least 1 in 6 adults in the UK are likely to experience mental health difficulties in any given week (McManus et al., 2009, 2016). The UK National Health Services (NHS) also survey children and adolescents; in 2017 1 in 9, 5–16 year olds had a probable mental health problem, and this had risen to 1 in 6 in 2020 (NHS Digital, 2018, 2020). But even before the extra strains of quarantine and school disruption, there was a particular worry that the number of young people developing problems with anxiety and low mood was on the rise (from around 4% in 1999 and 2004 to almost 6% in 2017, among 5–15 year olds), and the reported point prevalence of mental health problems among 17–19 year olds was high (16.9%), particularly in young women and was even higher in the 2020 data. In addition to the substantial challenges experienced by young people and their families, a further reason why these numbers are worrying is that the evidence suggests that half the lifetime cases of mental health problems in adulthood started before age 14 and three quarters before age 24 (Kessler et al., 2005).

The increasing numbers of children and young people with mental health problems means we are likely to have increasing numbers of adults affected in the future. So, in addition to improving well-funded prevention and intervention for mental health problems in children and young people, we must plan for an increase in the treatments, supports and services we will need to offer to adults. The increased demand is likely to come relatively quickly for both sets of services.

The pandemic has and will produce a double whammy – the effects of lockdown and the effects of economic slowdown that exacerbate existing socio-economic inequalities. During the first phase of the pandemic increasing difficulties were noted in younger people who are more likely to be in education or employment. For instance, the UK Office for National Statistics surveyed people in July 2019 and the same group during the pandemic (June 2020) and reported a doubling of the numbers to 1 in 5 reporting symptoms of depression. Younger adults (16–39 years) were more likely to report depressive

symptoms with about one third now reporting moderate to severe levels.

Even with current levels of mental health problems, we still have a treatment gap and long waiting lists (Alonso et al., 2018; Lawrence et al., 2015; Mandalia et al., 2017; Merikangas et al., 2011; Thornicroft et al., 2017), so are ill prepared to provide for the predicted even higher levels, including those following the SARS-Cov-2 pandemic. We need effective and cost-effective prevention, treatment and support as well as tackling these challenges at multiple levels (systems, community and individual). We already know a lot about mental health promotion, prevention, treatment and support, but this knowledge is yet to be implemented, and even if we know what might work, we often don't know the best way to provide it at scale or for marginalised groups. The demographic picture in the UK is also changing, with the population projected to surpass 70.1 million by mid-2029 and reach 72.9 million by mid-2041 (Office for National Statistics, 2019). There are also geographic trends with the four fastest growing boroughs being in London and the smallest growth being seen in coastal areas that have an increasing proportion of older people. Together with the projected increases in those living alone, these geographic and population growth differences will produce different types of strain on health and social care supports for the increasing numbers of individuals with mental health difficulties.

The prevalence of mental health problems, and the recognition of the wide-ranging effects of mental health difficulties, make the need for specific investment in mental health research vital so we can offer new solutions that keep pace with rapid changes in society. We need to understand the contributors to the increased numbers experiencing poor mental health and guide an investment strategy for tractable problems informed by the priorities of service users, their families and the services that support them. Any investment strategy needs to consider the spectrum of interventions from mental health promotion to support for long term conditions, so should include public health, social care, primary care, employment and educational services, housing, criminal justice, and community development and voluntary sectors, in addition to traditional mental health services.

### Building on mental health research priority exercises

Several roadmaps for research laid the foundations for this project and the pandemic has increased their number and added to the refinement. The first, the Roadmap for Mental Health Research in Europe (ROAMER) (Wykes et al., 2015) involved large-scale literature searches (e.g. (Evans-Lacko et al., 2014), an understanding of the funding landscape (Hazo et al., 2017), as well as consultations with 1000 individuals and organisations including service users. The subsequent priorities influenced research funding in European Horizon 2020 and the UK (e.g. (Medical Research Council, 2017)). Some of the later priority setting

exercises involving mental health service users concentrated on narrow issues which are important, but hard to integrate into general funding strategies (e.g. Hollis et al., 2018; James Lind Alliance, 2020; Lloyd & White, 2011; McPin, 2018; Nestsiarovich et al., 2017; Ormerod et al., 2018). There are also some led by service users that discuss different investigatory methods that should be used to develop the questions for research (Faulkner et al., 2015; Robotham et al., 2016).

The Five Year Forward View (Mental Health Taskforce, 2016) adopted the ROAMER priorities and recommended a 10-year strategy for mental health research. This led to the DHSC Framework for Mental Health Research (Department of Health, 2017) which identified barriers, suggested co-ordination improvement and a focus on areas where mental health research was likely to translate into significant benefits. Throughout that report, and the others cited here, the aim was to create opportunities for research that would have individual, economic and social benefit. Unfortunately, we did not have an idea of what sort of benefit, or over what time frame that benefit might occur.

The need for goal development was clear in an independent UK survey commissioned by the UK Academic Health Science Networks (AHSNs) which are responsible for implementing research findings into the NHS. UK clinicians and managers were asked what should be the focus of research and innovation and almost a quarter (23%) put mental health as a priority over the next three years with nearly three in five (57%) placing it in their top three priorities (The AHSN Network, 2019). This report, like others, highlighted child and adolescent mental health, multi-morbidities and the overlap of mental and physical health (Momen et al., 2020; Naylor et al., 2012; Pitman et al., 2012).

Further research priority exercises have now been developed out of a pandemic which has emphasised the urgent need for research (Holmes et al., 2020; Moreno et al., 2020; O'Connor et al., 2020). Inequalities such as ethnicity, health, age and sex, socio-economic status and their intersectionality are agreed as vital to consider in all mental health research and have been highlighted as moderating the effects of the pandemic. As well as drawing attention to mental health consequences, the pandemic also offers the opportunity to understand the importance of social contact, given the rules about physical and social distancing, together with research on how we can use those results to bolster prevention and support efforts.

The recommendations for reducing research barriers in the Framework Report (Department of Health, 2017) and these priority setting exercises are promising for surfacing vital evidence – if funding follows the suggestions. But we still have no clear goals or targets. Mental health research should be led by need, promising innovation and the potential for impact, and this impact should be measured using routinely collected data. But what was essential for this process was a consensus on the choice and reach of goals and their targets.

## Methods

The Chief Medical Officer for England in the Department of Health and Social Care called together a multi-disciplinary group made up of clinicians, academics, major mental health research funders, mental health research charities and representatives from service users groups, as well as representatives from Public Health England (a separate body responsible for interventions to improve population health) and the National Health Service (NHS) England. They were to consider high level mental health goals and begin to identify UK-specific targets to measure research impact. The process began in December 2017 and continued for three years.

Areas of concern to most of the participants and groups were identified – at this stage the ROAMER grouped priority areas were considered, and then, through discussion, a few highlighted goals were chosen. The wording of these goals was further developed by individual groups with expertise in each of the areas and included service users. Service user organisations were part of all the discussions, but to ensure that their views were well represented, a further round of consultation took place with individual service users from academia and service user-led groups, such as the National Survivor User Network, to ensure their agreement on the choice and wording of the goals. The goals changed until maximal agreement was reached.

This whole process took account of new scientific methods and evidence, the UK context with its benefit of a universal health care system (the NHS) and the embedded research support from the National Institute for Health Research (NIHR) Clinical Research Network.

This paper describes four mental health research goals which were the product of these discussions across the mental health sector. The goals are intended to be a guide rather than a set of limitations for funders and scientists. Monitoring progress against the targets will tell us where knowledge and/or implementation gaps continue and whether we should switch focus to other areas. They are based in the UK context, but many will resonate with mental health services and their users around the world.

## The goals for mental health research

The goals are presented not in their order of importance, but in a developmental order with children and young people first, and service level interventions last. The search for goals was intended to provide an overarching structure; hundreds could have been produced, but the list was limited to just four so everyone can focus efforts, build cross-sector partnerships, and track impacts. To know whether these goals have been achieved they need to be measured. Specific procedures may already exist, but some targets and goals will require novel assessments. In this paper, we have therefore suggested potential measures where they are available and potential avenues for further assessment development. We note that some work has already begun on such potential measures such as in the Implementation Plan for the Five Year Forward View (NHS England, 2016).

**Goal 1: Research to halve the number of children and young people experiencing persistent mental health problems**

We know that to improve the mental health of people in communities across the UK we need to focus on the early years, and reduce poor mental health among children and young people, and better address mental health problems as they develop. As well as bringing immediate benefits to children, young people, and families, this also has the potential to decrease the prevalence of adult mental health difficulties, and investment at this stage is also likely to have multiple benefits on educational outcomes and employment skills. Most exercises on mental health research priorities have mentioned childhood difficulties (Medical Research Council, 2017; Tomlinson et al., 2009), but our process has refined this focus to persistent mental health problems as they are likely to continue into or recur during adulthood. A concentration on mental health promotion as part of a broader public mental health strategy should also produce benefits for those whose mental health difficulties are more transient.

We have identified three evidence targets to address the overall goal.

- **Target 1A** Increase knowledge of the *aetiology, development* (including risk and protective factors) *and progression* of mental health problems at key transition points across the life course.
- **Target 1B** Increase research on *effective mental health promotion, prevention, treatment and support* in children and young people in education, community and health, including specialist mental health, settings.
- **Target 1C** Increase research on *implementation of effective interventions* in a range of settings to optimise outcomes. This includes research on service delivery and organisational factors influencing outcomes.

### Potential measures

The recent survey of child and adolescent mental health in England provides a baseline for this goal. The green paper on Children and Young people's Mental Health (Department of Health & Social Care & Department of Education, 2017) recommended that this survey be repeated every 7 years which provides a clear measure for many of these targets, including monitoring of equality. We will therefore know the changes over time in the numbers of children and young people with a diagnosable mental health problem. The survey also covers access to treatment and although two thirds of children have contact with a professional service, only one quarter have contact with a mental health specialist, and this is often not until after a considerable waiting period. In addition, there are surveys (e.g. YoungMinds, 2018) which highlight satisfaction with the services provided. We should notice the effects of increasing effective treatments for this age group by monitoring the

implementation of National Institute for Health and Care Excellence (NICE) guidance. This should show increases in the number of accepted mental health interventions for a larger number of mental health disorders, and, although records of effective school-based interventions are in their infancy (e.g. Early Intervention Foundation, 2019), they will provide monitoring information. There is an expectation in the NHS that routine outcome measures will also be collected by services providing interventions on behalf of the NHS for children and young people, so we should be able to monitor the number of people receiving a service, as well as the number who benefit from that service. Finally, data linkage across health, education and work would provide longitudinal outcomes especially for those who experience a mental health disorder in early life. This is possible and is beginning to happen (Downs et al., 2019).

**Goal 2: Research to improve understanding of the links between physical and mental health, and eliminate the mortality gap**

Nearly half the people (46%) with a mental health problem also have a long-term physical condition, and 30% with long-term physical conditions have a mental health problem (Naylor et al., 2012). These multi-morbidities increase the costs of care and physical health outcomes (Ismail et al., 2007; Zuidersma et al., 2012). For people living with severe mental health problems the risks are greater. They are over three times more likely to have a physical health problem and may die 10–20 years earlier than others in the general population (Chang et al., 2011). This is often called the mortality gap. There is even now some indication that they are more at risk of Covid-19 even after controlling for some risk factors such as obesity (Taquet et al., 2020). Most premature deaths are caused by potentially modifiable health-risk behaviours, such as tobacco smoking, alcohol and substance use, lack of exercise and obesity, in addition to social factors such as poverty, homelessness, and unemployment. Despite knowing these risk behaviours, changing them is complex as their origins may lie in past traumas and/or genetic predispositions, and so may be hard to change. But we still do not know how co-morbidities interact with each other and with social factors, although work on surfacing the underlying mechanism, including through the effects of different medications continues (e.g. Dregan et al., 2020; Momen et al., 2020; Stewart et al., 2009). An intervention for one problem might also affect another such as physical exercise having effects on wellbeing and physical health. It is only with this information that we can build towards eliminating the mortality gap.

- **Target 2A** Research to *strengthen our understanding of the co-morbidity of both mental and physical health problems*. This research should address clusters of health problems, underlying mechanisms and progression, and societal and individual risk and protective factors and in addition the implications for treatment and support.

- **Target 2B** Research to improve the *efficacy and effectiveness of interventions* for prevention of mental ill health and increase maintenance of good physical health for people living with mental health problems, or who are at risk of developing mental health problems. The aim is to reduce morbidity and excess mortality.

### Potential measures

Measuring intervening changes is more complex for this goal. But we would need to see a higher recognition of mental health difficulties in physical care with an improved implementation of current best practice. We also need to see increases in delivery of NICE defined interventions that are bespoke to people with severe mental illness. The progress to a zero-mortality gap will also be shown by improving health indicators of diabetes control, cardiovascular risk factors and smoking cessation. Detection and treatment plans for physical health problems could be measured through changes in Quality Indicators from primary and secondary care. Finally, measuring changes in the mortality gap can be achieved through successive analyses of the mental health minimum dataset or through the clinical records search systems now being implemented (e.g. CRIS: Stewart et al., 2009).

**Goal 3: Research to increase the number of new and improved treatments, interventions and supports for mental health problems**

A better understanding of therapeutic mechanisms for current drug and psychological treatments, social interventions and approaches to support developed by peers, would aid personalisation of treatment. This will include the exploration of the impact by geography, gender, age, sexual orientation, ethnicity, diagnosis, trauma history, poverty and other contextual factors. Studying potential mechanisms as well as the impact of new treatments or interventions for people with mental health problems should be on the agenda.

- **Target 3A** Research to *investigate the mechanisms underlying mental wellbeing, mental health problems and related behaviours* through use of markers from basic biological, psychological and social science to understand how to improve treatments, interventions and support.
- **Target 3B** *Develop and implement new and improved treatments, interventions and support*, including medical, social and psychological approaches to increase patient choice and greater personalisation.
- **Target 3C** *Develop and evaluate effectiveness of digital interventions* that complement and supplement face to face interventions for prevention, support and recovery.

### Potential measures

These individual targets are aimed at increasing effectiveness, decreasing side effects and identifying predictors of non-response to available and novel medical and psychological treatments. This will hopefully provide more treatment choices, taking into account the needs of different groups such as variations in need by age, class, gender, ethnicity, sexual orientation and geography, which could be measured through patient satisfaction and experience audits. We would also expect more NICE-recommended, and Medicines and Healthcare Regulatory Authority (MHRA) approved, technology enabled treatments to be available and acceptable to service users, as part of planned and staged treatments.

**Goal 4: Research to improve choice of, and access to, mental health care, treatment and support in hospital and community settings**

There is a failure to reach all the people who need care and support, as well as enabling them timely access to evidence-based treatment and support. We know that stigma and discrimination influence timely access, and that this influences outcomes (Marshall et al., 2005). Trust in mental health services and cultural competence also play a part. Investment in effective mental health promotion, prevention, and early intervention approaches have the potential to transform people's lives (Csillag et al., 2018), but we also need to understand if they can overcome the barriers to access. We need evidence on the cost effectiveness of different approaches through economic assessments of avoidable costs, both to society overall, and to individual families and service users themselves, by providing appropriate prevention and mental health promotion strategies. Poverty reduction, family and parenting support, housing provision, health promotion in schools and universal access to both specialist and primary mental health care, have all been linked with reducing mental health inequalities, so research will require partnerships with education and social care services as well as the voluntary sector. Recently suggestions have been made about the role of public services and local authorities in reducing the mental health inequalities (Centre for Mental Health, 2020). We still do not know how to choose or organise interventions to provide the most value for money, or how efficacious interventions from clinical trials might lose effectiveness when implemented into services. Rigorous evaluations of novel interventions in the NHS, voluntary sector, and local communities, as they are implemented, will improve the understanding of how changes to, or variation in, usual care practices affect patient outcomes. This type of research will require co-production including novel trial designs and access to large data sets, and embedded qualitative studies including service user-led research. It will also require an increase in whole system and implementation science approaches.

- **Target 4A** Research to *understand the barriers to help-seeking and service access*, and the delivery of mental

health services and other support in diverse settings and across different communities, including racialised communities and LGBTQ+, to address stigma, discrimination and social exclusion.

- **Target 4B** Research on how to *accelerate the implementation of existing best evidence* at the population and individual level. In addition, implement evidence on how patient choice and joint decision-making affects outcomes in routine care.
- **Target 4C** Increase research to *inform strategies for tackling social and health inequalities* to improve public mental health.

### Potential measures

Access to timely treatment might be measured in several ways including satisfaction and experience with services and supports as well as quality indicators of services, such as reversing the trend for increasing the numbers of people being admitted involuntarily to hospital as this may indicate an acceptance of hospital treatment at an earlier phase. Help-seeking by under-served groups, e.g. racialised groups, young men with depression, might be investigated via Hospital Episode Statistics. We also need information and evidence that people with mental health problems are living lives that they value, potentially by indicators of changes in the rate of increase in unemployment and reductions in insecure and inadequate housing.

### How can these goals be achieved?

Success in achieving these goals will be the responsibility of policy makers, research funders, and researchers. The goals provide a structure to enable these groups to work together to create clear plans for how they can be achieved. Key considerations will be multidisciplinary approaches and external partnerships and how service users will be at the centre. Methods from epidemiology and clinical trials, together with smart analytical techniques applied to a wide range of routinely available data, will provide some understanding of what new targeted treatments and public health interventions might achieve. Social and implementation science will allow an understanding of how these new approaches can be delivered effectively. But none of these methods can ignore the views of service users, their families and practitioners who will need to ensure the specific research questions explored will produce valuable answers. They will therefore need to be involved at all stages of the research process in meaningful ways, but particularly in the development and design phase. We also expect novel types of knowledge will contribute to reaching our goals, particularly new knowledge from the emerging fields of Mad Studies (Russo & Sweeney, 2016) of service user led research and co-production, such as in the 4PI document and the National Survivor Research Network Manifesto (Faulkner et al., 2015; Ormerod et al., 2018). External partnerships with the life sciences industries will be vital for developing drug and digital treatments. Working with the NHS and the

private and charity sectors will allow the further development and testing of novel ways of providing treatments including social prescribing. This multi-disciplinary and cross-disciplinary approach is already supported through the new UKRI mental health networks which brings research teams from different sectors, different expertise and different geographies under one umbrella. Other UK and international funders have also begun to emphasise the need for this approach. Finally, for the UK, the field will rely on different funders including UKRI, NIHR and charities to support different targets and different stages of the impact pathway.

### When do we expect these goals to be met?

Evidence from Rand Europe suggests that it can take 17 years for mental health research to be implemented into treatments and services (Morris et al., 2011; Wooding et al., 2013). Impact was faster if the researchers always bore in mind the eventual potential impact and considered how to engage with the impact pathway at an early stage. The research goals presented here are the most pressing and potentially tractable that could be accomplished within a decade or two. We have seen rapid changes in research and service configuration during the COVID pandemic, the effects of these changed services should be investigated, mechanisms for increasing the speed and efficiency of research should be maintained, and the results should then lead to accomplishing these goals.

We need to measure whether research to support these goals has been funded, how it has been delivered and by whom and whether it has led to patient benefit. This will require research funders to engage with the goals and, as they were involved in their development, we hope that this is an easy step. Monitoring these funding decisions will be important, because when research has answered our target questions then funding can be diverted into other areas. But we also need to measure the stages of patient benefit which will help to adjust our goals. The whole group has had many discussions on the risks associated with achieving the research targets, but then a lack of translation into impact. All changes will depend on wider political objectives and social context. But this does not alleviate the need for goals that will have an impact, as governments and those involved in mental health provision need actionable evidence for policy and services. Whether they choose to apply it may be outside the scope of many research teams. Evidence from the Rand report suggests that closing the research to impact gap requires teams to interact with the impact pathway at an early stage, and that means from the earliest basic research and throughout the translational pipeline. We also know that investment in research is lower in mental health than in other health conditions, and the latest evidence not only shows this, but also that these funds are not dispersed in ways that would answer our goals (Woelbert et al., 2021). We propose that goals and targets should be measured in short, medium- and longer-term intervals, perhaps of three, five and ten years, so we have a more detailed guide to how

research investment produces its effects, and most importantly, to identify barriers to patient benefit that need to be overcome. Engagement with the goals will then become a scientific and a political endeavour.

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




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