



Ten changes to  
*transform*  
**mental health  
research**

# Background

Mental health research has been historically underfunded; MQ Mental Health Research’s analysis of global mental health research funding found that for every person affected by mental illness, only £9 is spent on research<sup>1</sup>. In comparison, £228 is spent for every person affected by cancer. When mental health research accounts for 21% of the national disease burden, this is clearly not enough<sup>2</sup>.

Finding new and better treatments to help people to either recover from, or live long and healthy lives with, their mental health conditions should be a priority. People living with serious mental illnesses (SMI) die on average 20 years earlier than people not living with SMI, from conditions such as cardiovascular disease, diabetes and respiratory disease.<sup>3</sup> Mental health treatments such as antipsychotics are known to cause side effects that can contribute to these conditions in some cases.<sup>4</sup> People living with severe mental illness need access to a range of treatments so that they can find the support they need earlier and do not need to persevere with treatments that have the potential to cause devastating side effects. No one should have to choose between their mental and physical health.

“

The current treatments are not working for many people. In most cases treatment does not cure the condition or prevent it returning. People end up having to try many different treatments to find something that works and when it’s medication this takes time and all the time people are getting worse. Current treatment often makes people worse before it helps them which is the last thing someone suffering so much needs.”

Expert by Experience



## About Rethink Mental Illness

Rethink Mental Illness is the charity for people severely affected by mental illness. They are at the centre of everything we do. We provide services that support and empower people to live and thrive independently in their communities. We also provide local peer support groups across the country to help people living with mental illness and their carers support each other, grow in confidence, and take greater control of their lives.

We campaign at a local and national level to ensure people severely affected by mental illness are listened to, treated fairly, and have easy access to the health and social care services they need. We also work to elevate the voices of people with lived experience, including children and young people, in local health systems to create communities that genuinely care for the wide range of people we support.

Since 2023 we have been exploring our role in pushing for change around mental health clinical research. We have implemented a strategic objective to scope out the mental health research environment and identify the key challenges faced in the UK. This report sets out what we have learned and what we want to see change.



## About MQ Mental Health Research

MQ is a multi-award-winning mental health research charity. We invest in groundbreaking scientific research to help the 1 in 4 of us impacted by mental illness.

Since 2013 MQ has invested over £30 million to support 65 research projects across six continents.

Our scientists investigate a huge range of issues: depression, anxiety, schizophrenia, bipolar disorder, eating disorders and more. We are bringing together everything from cutting-edge neuroscience to social studies, data science and psychology to find the answers we need.

MQ’s research has already led to new discoveries, including a therapeutic intervention with a 99% success rate for people living with HIV and depression in Uganda, a new intervention for healthcare workers with PTSD with a 90% recovery rate, and new school guidelines on bullying and mental health in England and Wales.

Our approach is international, interdisciplinary and collaborative. Through research, we can make the next breakthrough in mental health by better understanding different mental health conditions, improving treatments and one day preventing mental illnesses altogether.

## This report

This report sets out what we have learned and what we want to see change across ten different, but often interrelated, areas. These changes have come from engagement with stakeholders and Experts by Experience (EbEs) that we have carried out over the past 18 months to uncover the key challenges that prevent impactful mental health research from taking place. These include face-to-face events in which we have convened stakeholders working in mental health research as well as EbEs, and an online survey which we distributed in 2024 asking EbEs about their views on and experiences of mental health research. This survey received 370 responses from people living with and carers of people living with mental illness.

# Our ten changes for mental health research

This section outlines ten key changes identified to transform the impact of mental health research. These are based on insights gathered from stakeholder events we held in partnership with MQ Mental Health Research to uncover major barriers in the field, engaging with Experts by Experience and wider conversations with stakeholders in the mental health research sector. **For each change, we have identified specific shifts that are needed and who can deliver them.**

1.

## Ensuring processes for recruiting participants onto research trials are systematic, equitable and maximise participation

Many people living with mental illness find it difficult to locate mental health research opportunities that are suitable for them, both in terms of participating in trials and participating in involvement opportunities. Our survey found that of those who consider themselves to have a mental health condition, 75.3% said that they had never been offered the opportunity to take part in mental health research.

We heard that these access challenges are particularly pronounced for particular groups, such as people from racially minoritised communities. This means that studies can often struggle to recruit adequate numbers of participants and research is often also not representative of the wider population of people living with mental illness. This can impact on research quality and applicability of the research for certain groups.

To address this, wide-ranging reform is needed to the way trial research opportunities are promoted, including routine promotion of trials by NHS

services. The Ten Year Health Plan's announcement that research opportunities will be available through the NHS App is a positive step towards increasing accessibility for research participation.<sup>5</sup> However, to ensure that a wide range of people (including those who are digitally excluded) can engage in research, these opportunities should also be advertised in trusted, community-based settings.

There should also be more collaboration with wider government departments, to ensure that there are more points to engage in research opportunities outside of the health system. One suggestion we had from someone with experience of engaging in research was to explore ways to create more opportunities for people receiving working-age benefits such as Universal Credit (UC) to play a significant role in shaping research projects. This move would have the dual benefit of directing people to meaningful activities that could increase their skillset and provide them with positive experiences, while boosting research involvement participation.

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When I was on benefits a number of times I was sent to a CV writing workshop and the problem wasn't my CV. It was that I was immensely unwell and incredibly suicidal. But actually I know that doing that research on the side did make that incredible difference. **So if we could encourage the Department of Work and Pensions to see the benefit for all people and lower that welfare cost budget.** Ideologically it works economically: it works: but it also would help us go further, **enriching the people that we need to reach to get them more involved in research.**”

Aphra Tulip-Briggs, Rethink Board Member and Expert by Experience

Engaging participants around research opportunities requires relationship-building and reassurance around topics that might cause concern, such as whether research participation would negatively impact their care or benefits. Roles like peer researchers or navigators may help to bridge the gap between participants and researchers.

Research and involvement activities must also be accessible in terms of the language used and the participation requirements. To ensure this, people with lived experience must be involved in designing research and researchers must be supported to enable this, such as by making their recruitment plans more equitable. Involving people in research will also help researchers to understand more about what motivates people to participate in research, which may improve recruitment at a population level.

## Identified shifts



People with lived experience must be involved in designing research throughout the research lifecycle



There must be accessible platforms where people can find out about research opportunities local to them.



Researchers must be supported to make their recruitment plans more equitable to enable a wide range of EbEs to get involved.

### Who can deliver these?

- Researchers
- Research funders



Exploring how wider government departments can promote and engage people living with mental illness in research opportunities (as participants and/or co-researchers)

### Who can deliver this?

Ministers and government departments

## 2.

### Increasing funding into mental health research to build confidence into the system and ensure joined-up working

As outlined earlier, funding for mental health research does not reflect the impact of mental illness on wider society. Of the funding that the UK does receive, the proportion from philanthropy and charity fundraising sources is much higher compared to other countries, where government/public funds are generally the main source of funding.<sup>6</sup> There is also concern that not enough funding goes into the development of treatments, with only 5.5% of total UK mental health research funding being used for this type of research.<sup>7</sup> Organisations such as Wellcome, MQ Mental Health Research, UK Research and Innovation (UKRI) and the National Institute for Health and Care Research (NIHR) have been investing in mental health research but there is more to be done.

We have heard that in many cases, funding calls are based around ambitious research projects that are innovative but might not directly impact on people's daily care. As explored later in this report, it is important that people see the impact of research in the form of tangible changes that improve people's care and access to treatments options, and so more funding should go to research projects that are more likely to impact on people's experience of care.

### Identified shifts

-  More private investment in mental health research
-  More public funding of mental health research

#### Who can deliver these?

- Private investors
- Research funders

-  Identification, prioritisation and funding of research quick wins to improve people's care and instil faith in mental health research

#### Who can deliver this?

- Research funders
- National Institute for Health and Care Research (NIHR)

Only

# 5.5%

of UK mental health research funding goes into developing new treatments.

## 3.

### Unlocking ability and capacity to conduct research in a variety of settings with a wide range of staff

There has been significant investment in mental health research infrastructure in recent years, with the establishment of the Mental Health Mission and the introduction of NIHR's Mental Health Research Groups (MHRGs).<sup>8 9</sup> However, the UK healthcare system is currently too stretched to meaningfully engage in research; capacity must be created in the healthcare system for impactful research to take place. Suggested improvements included increasing the number of adequate appropriate settings and equipment for conducting research in the mental health estate.

Experts have also suggested ways to enable non-research staff to engage in mental health clinical research, to boost research capacity. Addressing staff shortages in the NHS is a key step; without doing this, employers will find it impossible to make staff available for research. However, alongside practically creating capacity, there also needs to be a cultural change to ensure that non-research staff feel that they are part of a wider research team. Several shifts that could enable this include:

- Broadening the definition of research: Research is not limited to academia or clinical settings. Informal and applied research in healthcare, social services, and service improvement needs better recognition and support.
- Building a research culture: Long-term cultural shifts are needed, such as integrating research into early education, clinical training, and professional roles.

### Identified shifts

-  Protecting clinician time for engaging in research
-  Improving self-referral routes (e.g. making them more accessible) into research to take the burden off clinicians

#### Who can deliver these?

- Department of Health and Social Care (DHSC) / National Institute for Health and Care Research (NIHR)
- NHS organisations (NHS employers with responsibility for allocating work/capacity)
- Researchers/ research funders

-  Improved infrastructure for the delivery of research in mental health (e.g. imaging, community infrastructure)

#### Who can deliver this?

Integrated Care Boards (ICBs)



### Ensuring stigma around mental illness and mental health research is addressed

We know that stigma can have a devastating impact on many aspects of people's lives and experiences of living with severe mental illness. We have heard that it can have an impact on perceptions of mental health research as well.

Stigma and discrimination can prevent impactful mental health research from taking place. Stigma against people living with mental illness can lead to perceptions (i.e. amongst clinicians who might refer people on to research opportunities) that people with mental health conditions are too unwell to get involved in research. Unless someone has been judged to lack the capacity to decide whether they are well enough to engage, they should be given information about trials they could participate in and the opportunity to decide for themselves whether to apply.

Experts suggested the following steps to promote more positive attitudes to mental health research amongst clinicians.

- **Changing perceptions:** Promoting research as a collaborative activity rather than an individual burden. Introducing 'research champion' roles could help to encourage engagement.
- **Creating positive early career experiences in research:** Early positive experiences of research are essential to avoid disengagement and negative perceptions of research further down the line. This could mean

ensuring that research experiences are applicable to daily practice, or highlighting instances of research successes.

- **Addressing time pressures:** Clinicians currently struggle to prioritise research amidst urgent service demands. They need time and capacity to understand and engage in research.
- **Reframing language:** The language used to talk about research should reflect research's collaborative nature, i.e. not using terms like "subject", which can feel dehumanising.
- **Motivating and appealing to altruism:** Communicating long-term benefits of research participation, such as improved patient care, can help clinicians see the value of research.

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Mental health conditions need to undergo a radical paradigm shift into investigating, diagnosing and treating them as clearly 'physical' health conditions are (such as cancer or heart conditions). To make a parallel analogy, my current experience of mental health 'treatment' to date has been like giving someone various medications and talking therapies for cancer without actually identifying what the causes of the cancer are, doing specific diagnostic tests to investigate the precise type of it, and without monitoring whether medications/treatments are actually in any way effective.”

Expert by Experience

We heard that improving mental health conditions through more effective research has not felt like a key government priority and broader attitudes towards people who live with mental illness are related to this. Mental health conditions account for a significant proportion of the disease burden and inaction has and will continue to have a huge economic impact. As a sector, we need to ensure that mental health research is demonstrating impact and the economic case for mental health research is being communicated to policymakers.



“

Poor mental health is in epidemic proportions. I don't think the government cares. I often feel my life is already over.

Expert by Experience”

### Identified shifts

-  EbEs need to be included in a meaningful way and protected via appropriate safeguards.

#### Who can deliver this?

- NHS workforce
- Researchers

-  Mental health research and trials need to be embedded in the NHS
-  There needs to be a culture of innovation in the NHS

#### Who can deliver these?

ICBs

-  We need to share good news science stories as a matter of urgency with one voice across sector
-  Agree key measures of impact relevant for treasury

#### Who can deliver these?

The wider mental health research sector

-  Ensure measures of impact are included in research

#### Who can deliver this?

Researchers / research funders

## 5.

### Making mental health research more accessible and attractive for a wide range of staff

We heard that the mental health research workforce is failing to grow due to a lack of financial security, optimism around the impact and future of mental health research and a lack of resource and capacity to conduct impactful research. Several initiatives are already in place to support early career mental health researchers, such as NIHR's Mental Health Research Initiative and their Incubator for Mental Health Research<sup>10 11</sup> or MQ's own grant programmes for researchers who are launching their independent research. To build on this progress and address these issues in the long-term, we need to make mental health research an attractive option for early career researchers, by:

- Ensuring that there are opportunities for career progression and salary increases comparable to clinical practice
- Implementing flexible and long-term early career grants so that researchers are not constantly looking for the next funding opportunity
- Framing research careers in a positive light to communicate research's value and potential impact.

It takes a significant amount of time to train psychiatrists and so the workforce issues will not be solved by relying on research psychiatrists alone. Research needs to be opened up to a range of roles to ease workforce pressures in the short-term and so efforts must be made to upskill a wider range of roles to carry

out research functions. There also must be sufficient growth in the NHS mental health workforce to ensure sufficient staff to deliver initiatives such as Mental Health Act reform, Mental Health Support Teams in schools (MHSTs) and Young Futures Hubs, as well as sufficient staffing to engage in mental health research.

### Identified shifts



More flexible and long-term early career grants

#### Who can deliver this?

Research funders



Identifying which roles can be upskilled to carry out research functions

#### Who can deliver this?

NHSE officials responsible for workforce development (formerly Health Education England)



More opportunities for career progression and salary increases for mental health researchers

#### Who can deliver this?

ICBs



More positive framing of research careers in recruitment efforts for research roles

#### Who can deliver this?

Research institutes, academic institutions etc

## 6.

### Increasing the general public's trust around data

We heard of a general lack of public trust around how the NHS, researchers and the pharmaceutical industry use patient data. This, coupled with a general lack of awareness of how data can be used for public good can lead to public distrust around how data will be used for research purposes. However, we also heard that people are often happy to provide their data to trusted sources, when they know how their data will be used and how this will potentially lead to improved treatments for them and others. This is demonstrated through the 2022 MindKind study, which found that young people are generally happy to share their data to help others through research but are wary of sharing even anonymised data with governments or with private organisations.<sup>12</sup>

To address this, data needs to be collected with a clear purpose and people need to be able to see the impact of the data they have provided in their and other people's care. Good news stories around mental health research progress should also highlight the role and value of patient data in research breakthroughs.



People are often **happy to provide their data to trusted sources**, when they know how their data will be used and how this will potentially lead to improved treatments for them and others

Another key challenge is that it is difficult for researchers to extract data from NHS systems, which often act as gatekeepers to anonymised health records and have historically faced challenges with data linkage and sharing agreements<sup>13</sup>. The person who has provided their data should be the one to determine whether it can be provided for research and barriers should not be put in place by data custodians. Processes for accessing data for research purposes must be streamlined to enable researchers to access data where consent has been provided. The recently announced Health Data Research Service, funded by the government and Wellcome, hopefully should transform access to data for research processes by providing a single access point for researchers<sup>14</sup>.

### Identified shifts



Explore processes for streamlining access to data for research purposes

#### Who can deliver this?

ICBs



Communicating the impact of data in enabling impactful research

#### Who can deliver this?

- Researchers
- Research funders
- The wider mental health research sector





“

**My current experience of mental health treatment is like giving someone medications for cancer without identifying the cause.”**

Expert by Experience

7.

### **Enabling prevention and early intervention in mental health**

We heard that as mental illness affects so many areas of people's lives (including employment, housing, family and social connections among others), more needs to be done to understand the potential impact of new mental health interventions. For example, the Department for Work and Pensions (DWP) says that there are 790,000 working age people in the UK who are economically inactive due to long-term sickness and have a mental condition.<sup>15</sup> The availability of more and better mental health treatments (along with improved access to specialised employment support services and support for employers) may make a huge impact to people experiencing these conditions. This provides a clear example of how another government department has a role to play in enabling good mental health research, so that people are able to receive the treatments they need as early as possible. Mental health is not just about health, therefore any forthcoming government strategies around mental health should look at how different government departments and arms-length bodies can be activated and involved to enhance research.

### **Identified shifts**



Future strategies around mental health must detail how different departments and arms length bodies (such as DWP or NICE) can contribute to a thriving mental health research ecosystem

#### **Who can deliver this?**

Ministers and government departments



Better mental health interventions could **transform the lives of 790,000 working-age people in the UK** currently out of work due to mental illness – **showing why every department must act early.**<sup>16</sup>



8.

### Ensuring that progress made in mental health research is translated into policy and practical changes

While there has been significant mental health research progress, such as the development of new Schizophrenia treatment Cobenfy, these developments are not always communicated effectively to the general public and there can be low awareness of these updates as a result.<sup>17</sup> We heard that this perceived lack of progress in recent years has created the perception that it is not possible to make progress in mental health research. We need to ensure that there is a process for communicating positive messages around research as well as more collaboration between researchers and influential organisations to ensure that positive stories are heard.

Another identified challenge was that research is not resulting in enough practical changes in people's care. The NIHR Mental Health Research Translational Collaboration was established to address this very issue, as it aims to bring together a variety of stakeholders to ensure that mental health research translates into changes in clinical practice.<sup>18</sup> This work must be built upon to ensure that new developments in research are resulting in new treatments and approaches to care.

We need to ensure that there is a process for communicating positive messages around research.

### Identified shifts



More collaboration between researchers and organisations with influence/ media connections to ensure positive stories are heard

#### Who can deliver this?

- Researchers
- Research funders



More collaboration between researchers, clinicians and policymakers must be enabled

#### Who can deliver this?

Research funders

9.

### Exploring new methods and research settings

The types of methodologies used to evaluate new treatments may also be a barrier to widespread research. Randomised Control Trials, in which participants are randomly assigned to either an experimental group (in which a new treatment is administered) or a control group (in which an existing treatment or placebo is administered) are seen as the gold standard of evidence for new treatments. However, these are lengthy and challenging to run, which may delay the process of obtaining evidence for new health technologies.

For non-pharmaceutical treatments, there are various emerging methodologies which may be more effective at generating evidence and can be used in a wider range of settings, such as primary care and community settings. These settings may be more relevant to the daily lives of people experiencing mental illness, as this is where the majority of whom receive treatment, and can facilitate research at critical time points, such as when people are on healthcare waiting lists. To facilitate research in these settings, a wide range of research methods may need to be considered, such as participatory research method and qualitative studies. Service delivery staff need to be supported to develop their research literacy and the findings need to be accessible to enable local implementation. Lord O'Shaughnessy's review of the commercial clinical research landscape also pointed out that very little research takes place in primary care, despite its potential for delivering population-scale trials.<sup>19</sup>

### Identified shifts



Regulatory bodies need to consider whether RCTs are necessary for all types of technologies and if a wider range of methodologies is appropriate.

#### Who can deliver this?

Regulatory bodies such as MHRA, NICE





### Enabling wider research stakeholders to collaborate

To ensure that effective mental health research can take place, collaboration between a wide range of stakeholders must be enabled. There are many examples of good practice, such as the Wellcome-funded GALENOS and MQ-funded IDEA projects, which supported researchers from different scientific disciplines to work together and share their knowledge and expertise, but there is still more to be done to go to break down siloes between different research stakeholders.<sup>20 21</sup> Voluntary, community and social enterprise (VCSE) organisations are well placed to help address barriers to recruitment onto studies as they work closely with Experts by Experience at a local level and may hold service data that would effectively identify candidates for research. However, many VCSE organisations lack the resource, capacity and awareness of research opportunities to effectively engage with the research ecosystem. To enable this to happen, resources and education around research practice is needed.

As outlined earlier, Experts by Experience need to be meaningfully involved in shaping research design and priorities to ensure that research projects reflect the key priorities of people experiencing mental illness. As well as removing access barriers as outlined earlier, lived experience involvement must be routinely included in mental health research studies.

### Identified shifts



Ensuring that all research has a lived experience component, e.g. a PPI statement

#### Who can deliver this?

Research publications



Funding for the VCSE sector to be able to dedicate time to research.

#### Who can deliver this?

Research funders



**Experts by Experience need to be meaningfully involved in shaping research design and priorities.**

**Mental health research isn't a luxury – it's a matter of life expectancy, equality and hope.**





## Conclusion

The results of our investigations have shown us that mental health research is not just the responsibility of researchers and research funders. We all have a part to play in ensuring that there is a healthy UK research ecosystem. To enable this to happen we need more joined-up research collaboration in the UK to promote a healthy research ecosystem and ensure that a wide range of stakeholders, including but not limited to, wider government departments, the VCSE sector and Experts by Experience, know that they have a role and what this is.

More investment is needed, building on the positive steps taken in recent years, but funding is not enough. More capacity is needed in the health system to ensure that the mental health workforce can engage in research, and broader cultural shifts must happen to tackle the impact of stigma on mental health research and promote a more positive view of mental health research and its potential for change. We need to think outside the box of traditional forms of data collection, research methods and research settings to ensure that research studies can be rolled out quickly and collect real world evidence.

This is our vision for what needs to change to ensure that the UK has a thriving mental health research ecosystem, that ultimately enables people living with mental illness to access new and better treatments that support their mental and physical health. There are already many initiatives in place to address the challenges identified in this report; we hope to see more investment, focus and championing of mental health research to close the gap between mental and physical health research and ensure that all stakeholders see mental health research as a priority.

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All my life I've taken old drugs for my bipolar disorder, nearly all designed for other human illnesses.

The exception is lithium, invented in the 1940s. It was tried on patients after being found to calm pigs. The rest were treatments for other human illnesses.

Two anti-epileptic medications, one invented in 1953, another in 1962. One of the most effective was the anti-depressant phenelzine – invented in 1932. A breakthrough for me was the 'cutting edge' drug nimodipine – invented in 1971 for brain haemorrhages.

Psychiatrists are plain that psychiatric drugs, mostly repurposed like these, just dampen down the symptoms, but are designed to treat the cause. There have been no major breakthroughs in drug development for severe mental illness this century.

But brain science has progressed in leaps and bounds and progress is tantalisingly close – our time has come. Don't we deserve effective, modern treatments, just like people with serious physical health conditions? Or do we not belong in the 21st Century? The nagging suspicion is society, policy-makers, pharmaceuticals and researchers have other more pressing priorities.”

Robert Westhead, Rethink Supporter and Expert by Experience

“

**Don't we deserve effective, modern treatments, just like people with serious physical health conditions?**”

Expert by Experience

CAMPAIGN  
FOR  
CHANGE



## Endnotes

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No one should have  
to **choose between**  
their **mental** and  
**physical health.**

**Rethink  
Mental  
Illness**

We are the charity for  
people severely affected by  
mental illness, no matter  
what they're going through.

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