

# Everywhere and everyone included?

Research in NHS Mental Health Trusts in England



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# Executive Summary

The Government's policy is that all NHS trusts in England should be research active. The NHS constitution implies a right for people using NHS services to participate in research. However our analysis shows that research in mental health trusts remains largely concentrated in a few places.

This matters because:

- It reduces opportunities for people affected by mental health problems to participate in research and the benefits that it can provide.
- Involvement in research should be part of mental health professional's training and ongoing professional development.
- There are well documented issues with recruiting sufficiently large and diverse numbers of participants for research studies. Effectively restricting recruitment to a small number of trusts limits the pool of potential participants.

Discussions with Research and Development (R&D) managers in mental health trusts highlighted a number of barriers to supporting research in their organisations. A number of these are influenced by the need for up-front investment to develop a research programme, which is difficult to recoup through research grants.

If research activity improved other elements of a trust's performance it might be easier for trusts to justify investment in it. A link between research and improved patient outcomes is often cited by NHS R&D departments. This would be a strong argument for investment. However, our analysis did not find an obvious relationship between increased research activity and a trust's inspection scores in the available data. Therefore although investment in mental health research in the NHS is clearly in the wider interests of patients and the service nationally; for individual trusts already struggling with funding reductions it may be difficult to justify significant new investments on the current evidence.

Stronger national leadership is needed from Government if it wants to spread and grow mental health research in the NHS in England. Existing research networks that receive the majority of funding should be encouraged to collaborate with new partners. Innovative practice that reduces the barriers to research locally, for example making participant recruitment easier, needs to be supported. The case for local investment in research needs to be strengthened or the incentives changed.

A number of barriers will require national and local collaboration to overcome. These include the perceived lack of a research culture amongst mental health professionals; the lack of charitable and commercially funded research; and raising the aspirations of people who use services about their rights to ask about opportunities to participate in research. These are challenges not just for Government and the NHS, but also for professional bodies and charities, like the McPin Foundation, that advocate for mental health research.

## Introduction

The NHS constitution commits the NHS to informing all patients “of research studies in which you might be eligible to participate”.<sup>1</sup> This includes users of mental health services.

In 2012 the Government committed to creating a “culture of innovation and research that is embedded at every level in both the NHS and public health”.<sup>2</sup> It has mandated Health Education England to “develop a workforce that embraces research and innovation”.<sup>3</sup> The National Institute for Health Research (NIHR), which funds, facilitates and promotes research in the NHS in England, has celebrated the fact that all English NHS Trusts were ‘research active’ in 2015/16, i.e. they had been involved in at least one NIHR funded study.<sup>4</sup>

There is therefore a clear expectation that research activity should be spread across NHS mental health trusts in England, and that the people who use their services will be given the opportunity to participate in research.<sup>5</sup> We wanted to explore if these expectations were being met and to understand:

- The spread of research activity across English NHS mental health trusts – taking into account the size of trusts and the fact that not all research is NIHR funded.
- Whether there is a trust-level link between how research active trusts are and high level indicators of service quality. A clear link between service quality and levels of research activity would be a strong motivation for the leadership of trusts to invest in research.
- What the barriers are to spreading research activity across mental health trusts and how they might be addressed at a local and national level.

### Our approach

We built a database of research activity in mental health trusts in England that were operating during financial years 2013/14 and 2014/15. Included in this were:<sup>6</sup>

- The number of NIHR studies a trust recruited to and the total number of patients recruited to studies in each year according to the NIHR league tables in 2013/14 and 2014/15 (the latest financial years available at the time).<sup>4</sup>
- The number of publications catalogued on Web of Science in 2014 and 2015 that included at least one author who listed a relevant trust as an affiliation, and the number of citations these publications received. This was in order to capture some of the research activity not funded by the NIHR. These are limited as measures because we cannot be certain that all authors would list any trust they were affiliated with, where a paper included authors from more than one trust it was counted against both. It was not possible to search by financial year.
- Trust’s income for financial years 2013/14 and 2014/15 as recorded in their annual reports as a measure of their size.
- Trusts’ latest overarching Care Quality Commission inspection scores and relevant results from the CQC’s 2015 Community Mental Health Survey, indicators of the trust’s overall performance that are likely to influence strategic decisions by senior leadership in trusts.

We held (with the assistance of the NHS R&D Forum) two virtual roundtables with members of research and development teams from seven English NHS mental health trusts drawn from outside of the ‘academic golden triangle’ of London, Cambridge and Oxford to test our data and to discuss the barriers to research in mental health trusts and potential solutions.

Limited resources restricted our analysis to mental health trusts. In reality the majority of people affected by mental health problems are treated in primary care, and there is a growing appreciation of the interaction between mental health and physical conditions. Therefore we have not captured all research activity within the NHS that is relevant to mental health. Based on our discussions some of the issues identified below are likely to have wider application to other health specialties and providers. For example the 2016 UK Renal Research Strategy identified concerns about a shortage of research opportunities for patients and a need to streamline 'consent for contact' about research into kidney diseases.<sup>7</sup>

## Why the distribution of research activity is important

There are a number of arguments for a national policy of encouraging all mental health trusts to be research active:

- High quality research in healthcare settings is needed as part of the pathway to developing and testing new interventions and ways of working that will improve the lives of people affected by mental health problems, now and in the future. Mental health diagnoses and treatments are known to be sensitive to cultural factors and therefore need testing on diverse populations and in different settings.<sup>8,9</sup> This suggests a need for a diverse range of sites able to host studies.
- There are well documented problems with recruiting sufficient participants for studies, especially ones with detailed exclusion criteria.<sup>10,11</sup> The more trusts who are able to support research the larger, and more diverse, the potential pool of participants. We also heard anecdotal reports that some local services in the most research active trusts are "fished out", with both users and, especially, clinicians becoming

jaded by repeated, uncoordinated, requests to participate in studies.

- There is some evidence that research active clinical teams deliver better outcomes for patients, including those not personally participating in studies.<sup>12</sup>
- Familiarity with research, and translating it into evidence based practice, should be a core part of training and continuing professional development for healthcare professionals. This implies all trusts that provide training should provide opportunities for trainees to become involved in research.<sup>13,14</sup>
- Service users, when asked, are generally interested in becoming involved in research. They also tend to benefit from doing so. Research participants tend to have improved health outcomes and also report improved wellbeing linked to increased feelings of empowerment and/or having made a contribution.<sup>15</sup> In 2014/15 only 2%, at most, of patients in contact with mental health services took part in a NIHR funded study compared to the 19.6% of cancer patients who took part in research.<sup>16,17,18</sup>

There are however also arguments for concentrating research activity:

- Developing and delivering research studies requires investment in infrastructure. This includes staff and systems to support researchers to design studies, apply for and manage funding, to recruit participants, and disseminate the results, as well as the space, equipment and staff needed to actually deliver the research study. R&D managers report that this is easier to fund in larger trusts, where it is a smaller proportion of their overall budget, or in concert with partners.
- To compete in the global market for talent and funding there is probably a limit to the number of world class institutions England can support.

- The limited investment in mental health research, especially from commercial and charitable sources, places a limit on how many studies are possible and the extent to which trusts can use income from hosting external research to cross-subsidise their own research or other activities.<sup>18</sup>
- Multi-site studies are substantially more complex (and therefore expensive), especially if the sites are geographically dispersed.

Being research active does not necessarily mean a trust must originate or lead studies. Acting as a recruiting site or host for studies led or co-ordinated from elsewhere would deliver many of the benefits identified above, particularly increasing patient access to research and providing development

opportunities for professionals. It still allows for the continuation of a model where a limited number of centres of excellence lead such collaborations capturing the benefits from specialisation and from the agglomeration of the limited number of world class researchers.

The Government has made the policy decision to seek to spread research activity across the NHS in England. Given the constraints they face, and the competitive funding model adopted by the major research funders, our discussions with R&D managers suggest most trusts have prioritised hosting research led by others. In other words they focus on recruiting participants from amongst the people who use their services and or make available the trusts facilities for use by researchers, rather than developing research studies 'in-house'.



## How Research Active are Trusts?

There is substantial variation in the size of mental health trusts, both in the number of people who use their services and the range of services provided. Annual income ranges from approximately £40 million to in excess of £400 million. Larger trusts have a deeper pool of staff to potentially lead research and more service users to recruit research participants from. If research activity was evenly spread we would therefore expect the larger trusts to be doing proportionately more. NIHR do not take size into account in their annual league tables.

Following Mitchell and Gill we created rankings of trusts on the number of NIHR studies they participated in, the number of research participants they recruited to NIHR studies, the number of times authors affiliated to trusts were listed in publications on the Web of Science, and the number of times those articles have been cited.<sup>6</sup> We then summed each trusts individual ranking and re-ranked them to produce an overall research activity ranking. We also ranked trusts by income.

The inverted research and income rankings (so the least research active trust and the trust with the lowest income scored 1 and the highest 56) are plotted in figure 1 (below). If research activity were spread relatively evenly we would expect to see a relationship between income rank and research activity rank. As is obvious from figure 1 the relationship is very weak [ $r^2 = 0.17$ ].

The charts in figure 2 show the different measures of research activity per trust divided by their turnover. The listing of trusts is consistent between charts. We have not listed trust's names as our focus is on the national picture.

Again it is obvious that there is a wide difference between trusts levels of research activity, even when their size is taken into account. It also suggests that purely relying on the NIHR's league tables would lead to underestimating the relative level of research activity in some trusts. Therefore, despite the NHS constitution and NIHR's efforts a user of mental health service's ability to participate in research appears to depend largely on which trust catchment area they happen to live in.

Figure 1: Total Research Score against Total Income

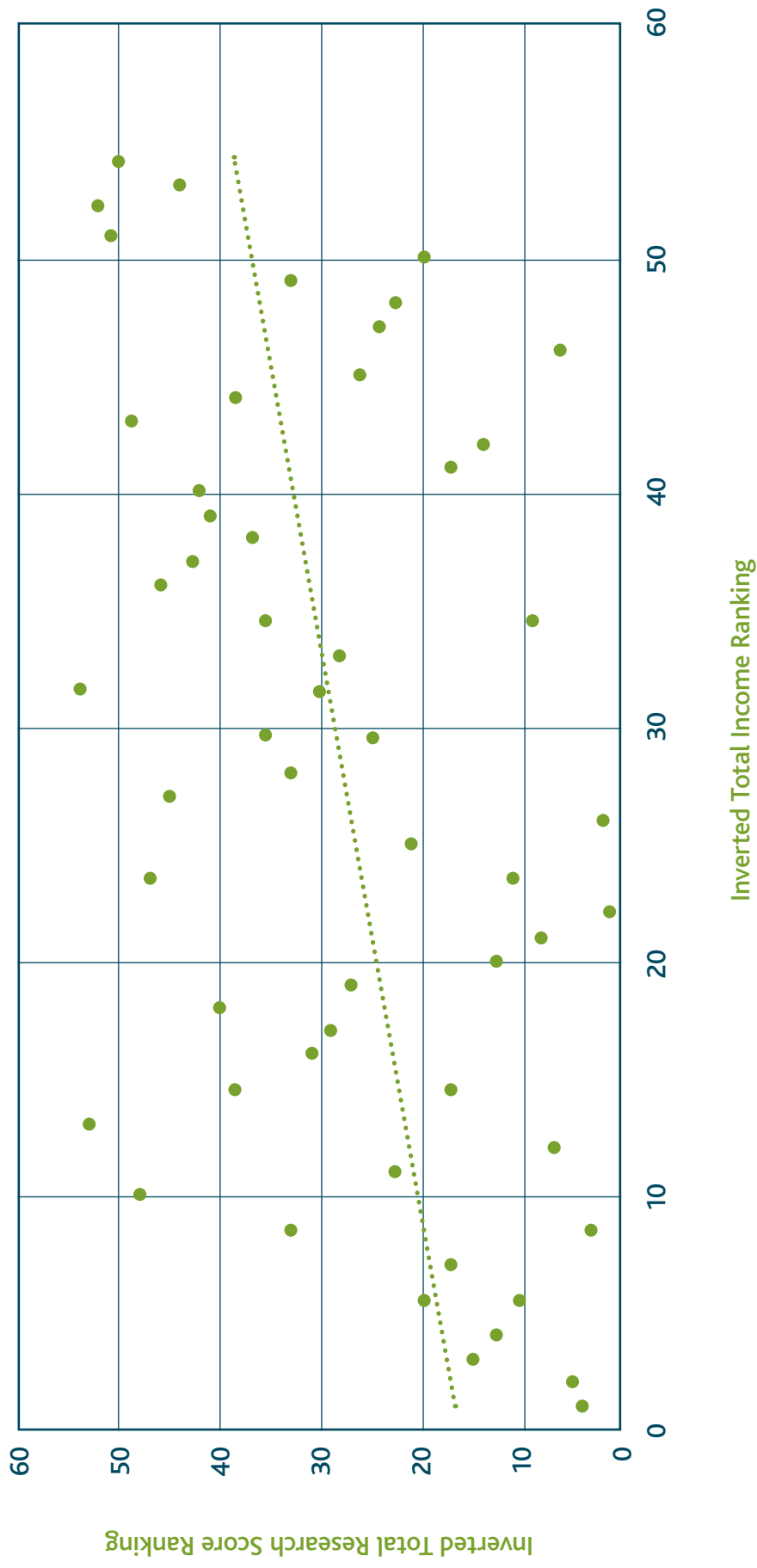
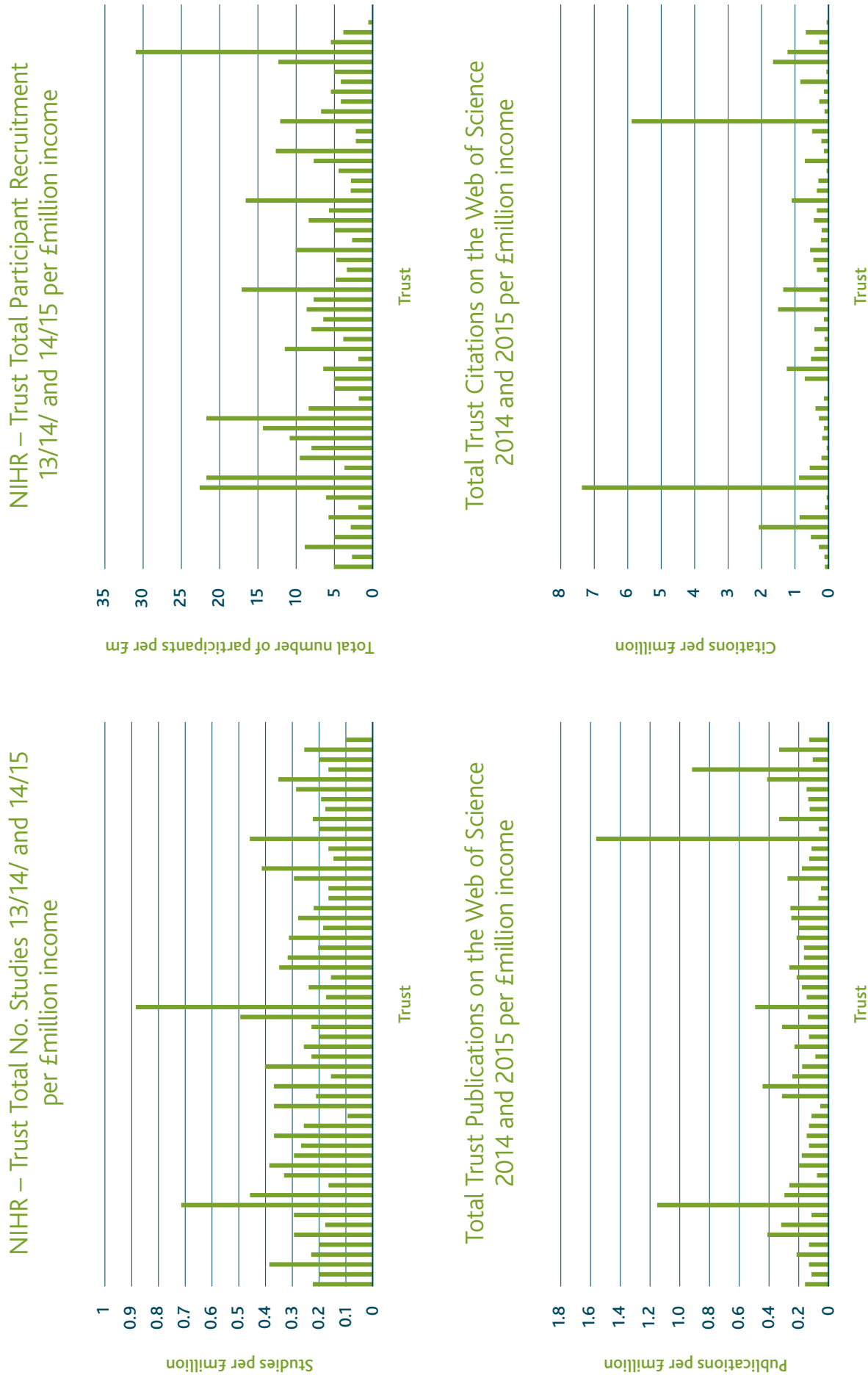




Figure 2: Distribution of different forms of research activity controlled for income – trust order is consistent



## Barriers to Research in Trusts

In discussion with research and development (R&D) managers the following barriers were identified to hosting studies led by others:

- A perception that many NIHR funded studies are designed to be single site, to reduce cost and complexity. For obvious reasons these tend to be hosted by the trust that the lead investigator is affiliated to.
- Multi-site collaborations are often arranged on the basis of existing, personal or institutional, academic networks. Understandably given the added complexity of multi-site studies researchers want to work with collaborators they have confidence in. R&D managers report that trusts without staff who are part of these networks, or who do not have a significant track record of hosting studies, struggle to 'break-in'. One trust described how recruiting two established clinical academics to work in the trust had noticeably increased the number of studies they had been asked to host.
- Trusts that are geographically distant from London or other major academic centres, or cover a large geography making recruitment within the trust difficult, are, 'out of sight and out of mind' when it came to attracting studies as one R&D manager put it.
- A relative lack of commercial or charity funded research in areas other than dementia.

Some trusts have invested in developing their own programme of research rather than rely purely on hosting others. This is obviously easier for trusts with close links to large medical schools and universities; but all the trust R&D departments we spoke to reported some form of activity to encourage their staff (from all professions) to develop their own research. In many cases this research will not be NIHR funded, which is why it is important not just to rely on the NIHR league tables to measure research activity.

R&D managers reported a number of more general barriers to research in their trusts, whether developed in-house or hosted:

- Researchers often need the support of health professionals to identify and recruit people who use their services who might be eligible for studies. In most cases they need to give prior consent to being contacted by researchers about studies they may be eligible for. However, many professionals are reported to act as 'gatekeepers' rather than facilitators. This may be through discouraging service users from taking part in research; taking an overly risk-averse approach to their capacity to participate or consent; or just failing to ask on admission to a service if a patient would be happy to be contacted by researchers. In 2010 the Medical Research Council highlighted the fact that many mental health teams saw research as an 'undesirable interference' to their work as a barrier to studies in NHS mental health services.<sup>19</sup>
- A relative lack of a research culture in psychiatry, and other mental health professions, compared to other specialities such as oncology. In 2013 the Academy of Medical Sciences reported that number of academic psychiatrist posts in medical schools had fallen by over 25% since 2000.<sup>13</sup> More widely it reported ongoing issues in recruiting students to the specialty, in part because of a perception that it is less scientific than other branches of medicine. The MRC and NIHR report that they receive relatively fewer applications for training and other fellowships from mental health professionals, although success rates of applicants is in-line with other specialties.<sup>19</sup> In our discussions R&D managers pointed out the potential for a vicious circle. The limited opportunities for the current generation of mental health professionals had to get involved in research while they were trainees, meant that fewer had the experience, or desire, necessary to embed a research culture once they

reached leadership roles. This is now restricting opportunities for the current generation of trainees. This is not just an issue for psychiatry, and many trusts are also seeking to encourage research by nurses and other professionals.

- The up-front investment required to develop research studies and win grants. R&D managers identified the main problem as being the cost of staff time, both clinical and in R&D teams, required to develop proposals and write grant applications rather than the cost of physical buildings or equipment. All reported that grants from the public sector for specific studies did not cover these overheads. Two reported using income from commercial dementia research to subsidise their other research programmes. NIHR does provide some funding for general costs in the form of Research Capability Funding (RCF), based on how successful a trust is in winning grants or recruiting research participants. However in 2016 twenty-five out of fifty-six trusts received no RCF and six the £20,000 minimum.<sup>20</sup> All the trusts we spoke to reported that RCF did not cover their overheads, and of course would not be available for the up-front investment necessary to expand a research programme.
- R&D managers also speculated that the people who use mental health services are unlikely to proactively ask about or search out research opportunities, in part reflecting the wider lack of a research culture in mental health also reflected in the low levels of charitable giving. If true this would mean that trusts and individual medical professionals are less likely to be prompted to think about or justify a lack of research activity. The annual National Cancer Patient Experience Survey includes questions about whether people diagnosed with a cancer have been asked about research opportunities, broken down on a trust and CCG level.<sup>21</sup>

The final issue that our round-tables identified was that R&D departments felt peripheral within their trusts and the wider system. For instance they were not routinely examined in CQC inspections, even when the trust leadership suggested them as an example of excellence. R&D managers did not perceive a demand from Trust leadership for them to provide a source of evidence or ideas to inform future strategy or practice – as might be expected of a research function in a private sector company. Where hospitals do have a research history or culture the R&D team are often hosted by, and seen as part of, an academic partner rather than the trust. This has obvious advantages in leveraging the expertise of academic partners in developing and delivering research, but it may reinforce a sense that research is not part of the trust's core business.

## What can be done?

Our round tables and other discussions identified a number of steps that could be taken locally and nationally to increase research activity in mental health trusts. Some of these are discussed below. Committed and sustained leadership, both nationally and locally within trusts, was an overarching issue. Within trusts it is required both to change cultures and to be willing to make the up-front investment in staff and infrastructure necessary to develop and grow research programmes.

A number of trusts are already taking steps to address the issues they face locally in recruiting participants to studies. There are, for example, local initiatives intended to overcome the unhelpful aspects of the 'gatekeeper role' played by clinical staff. Some trusts are trialling centralised registers of the people who use their services who have consented to being contacted directly about participation opportunities they might be eligible

for, combined with searchable patient records to help researchers identify potential participants.<sup>22</sup> Some trusts have gone further by introducing an opt-out approach to consent for contact about research, with the active support from service-users who have been engaged in designing the approach.<sup>23</sup>

A different approach has been to embed research assistants within clinical teams on a permanent basis rather than for individual studies as is the traditional model. This seeks to provide a bridge between researchers and clinicians, giving both sides a better insight into the pressures on the other. It also facilitates identification of potential participants in research within routine team meetings and for the implications of their participating in a study to be considered as part of their wider care.<sup>24</sup>

However these approaches require upfront investment, and a large enough portfolio of studies locally to make it economic.

### Is it in individual trusts interests to invest in research?

We therefore wanted to consider what might persuade a trust leadership that it was worth investing in research, and the infrastructure to support it, especially given the lack of direct financial returns. The obvious answer, based on our discussions, would be to demonstrate that research active trusts deliver better results on the measures of quality that would be expected drive a trust leadership's behaviour. The argument that research active institutions deliver better outcomes for patients is widely cited.<sup>25</sup> As noted above there is evidence that this is true for some specialties at the level of clinical teams. However, it is reasonable to assume that to incentivise a change in a trust's overall strategy there would need to be an observable impact at a trust wide level.

We therefore looked at whether there was a relationship between a trust's level of research activity and their CQC inspection results and user satisfaction levels for community services, as measured by the community mental health survey.<sup>26,27</sup> We used these as the measures most likely to influence the leadership of a trust.

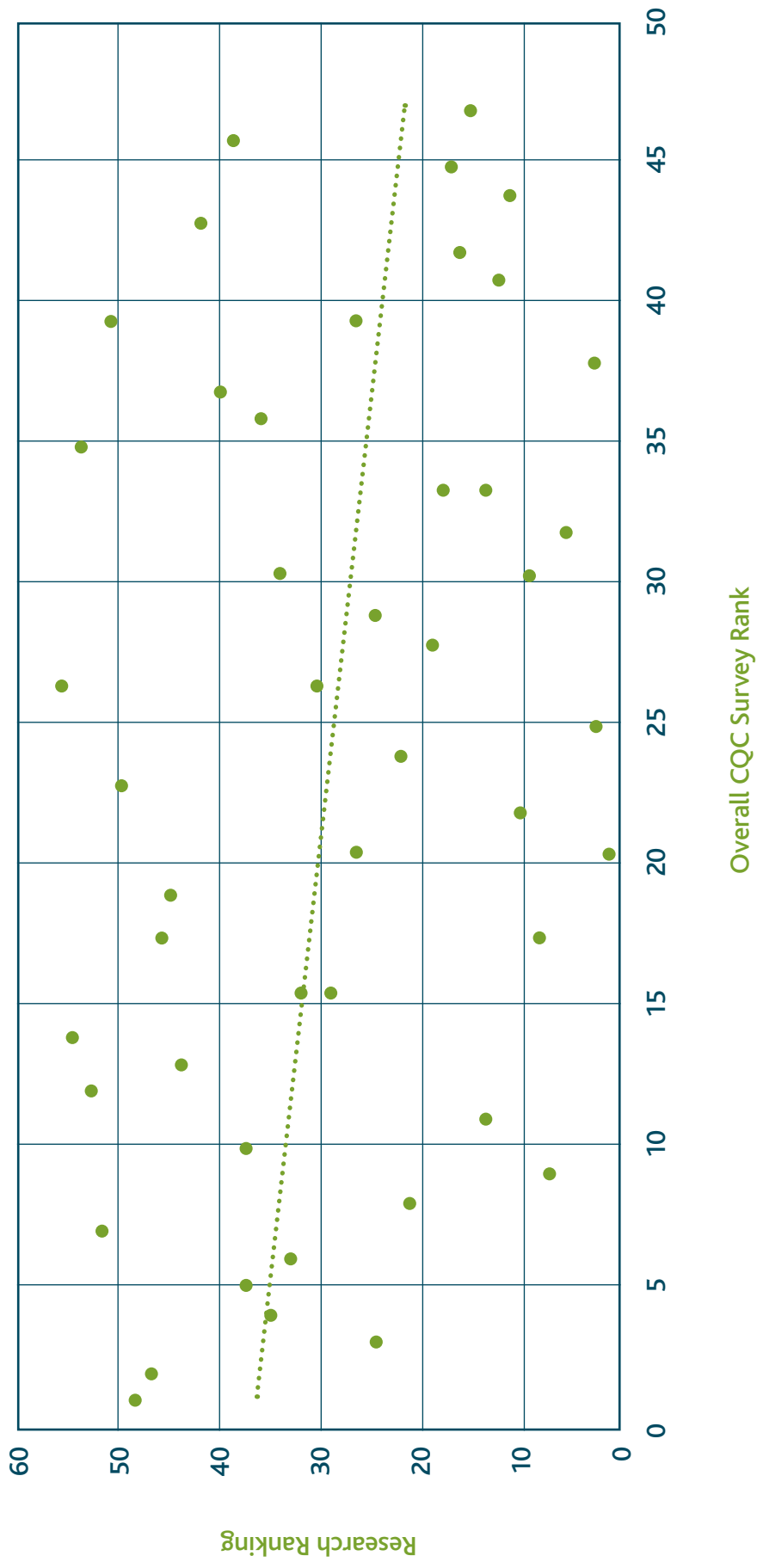
We created a ranking of trusts by research activity (relative to their size), and a separate ranking of a combination of their CQC inspection results and ranking in the community mental health survey. If there was a relationship one would expect that trusts that placed highly on the research activity ranking would also rank well on the quality measures. As can be seen from Figure 3, below, this is not the case [ $r^2 = 0.07$ ]. This of course does not disprove a link between research activity and outcomes for people using services. But on the available data it is difficult to make a compelling case for investment at trust wide level at this time.

Of course there are other reasons why trusts may decide to invest in research. Because they recognise the benefits it can bring to the people using their services and professionals. They believe that it is part of their wider responsibility to patients and the NHS. Because it can help in attracting and retaining high quality clinical academics and provides intangible benefits to the standing of the trust.

However at a time of reducing budgets and increasing demands on services it is unlikely that these intangible benefits will drive the significant investment in research infrastructure in trusts that delivering the Government's aspirations implies.

So national leadership will be vital if the government is to achieve its desire to spread research activity. Further work is required to build the case for investment, develop the most effective ways of doing this, given both the wide range of barriers that have been identified and the ongoing fiscal constraints. The forthcoming 10 year strategy for mental health research provides an opportunity to set the tone however.

Figure 3: Research Ranking against CQC and Community Survey 2015 Ranking



## Recommendations for national policy makers and next steps

Based on our analysis and discussions with R&D managers we would recommend that Department for Health and NIHR examine options for:

- a. Testing the perception that researchers tend to operate within their existing networks by incentivising projects that build new collaborations between institutions and/or involve different populations.
- b. Ensuring that funding decisions, both for research grant programmes and for investment in infrastructure, take into account the relative paucity of commercial and charitable funding for mental health research compared to other specialties.
- c. Further research is needed to quantify the relationship at a trust wide level between research activity and other aspects of a trust's performance such as outcomes for patients.
- d. Making the NIHR research league tables a more powerful tool by capturing activity that is not NIHR funded, and taking account of the size of trusts. Advocates for research, including in the charity sector, should use this data to ask questions of those trusts who appear to be underperforming. Further work is needed to understand the reasons for the differences in individual trust's performance.
- e. Examining whether support can be given to disseminating and championing new ways of working that reduce the cost and barriers to research. Discussions are already happening about spreading the techniques for increasing recruitment outlined above. We would not recommend the development of a national system, or imposed standards. However a number of R&D managers expressed enthusiasm for national co-ordination of the evidence for such an approach, especially its acceptability to service-users, and what works so they do not have to 're-invent the wheel'. This may be a role for bodies such as the NHS R&D Forum, or a mental health sub-group of it, if properly resourced.
- f. Establishing and monitoring whether people using mental health services are aware of and assert their rights to be informed about opportunities to participate in research. It is likely that targeted efforts, further to the general 'Ok to Ask' campaign led by NIHR, will be required.<sup>28</sup> This may be an area for collaboration between the NHS, the academic community, research charities, and service user groups.
- g. Working with the Royal Colleges, other professional bodies, universities and trusts to reinforce the position of research within the training and CPD for all mental health professionals, and to encourage trainees and professionals to seek out research experience as part of their development. At a minimum this would require there to be sufficient accessible opportunities for trainees to gain experience of assisting with a study.

As a number of our recommendations make clear this is not just an issue for national policy makers. A number of mental health trusts are already collaborating to share best practice, and our round-tables demonstrated there is enthusiasm to learn from each other and other specialties.

The charity sector also needs to consider how it can support mental health research in the NHS. One role will be continue to advocate for high quality research to be prioritised in national policy and properly funded, including increasing charitable funding. We need to think more about how we work with researchers and the NHS to build the interest in research amongst people affected by mental health problems, including asking about opportunities to participate.

In the coming months the McPin Foundation will seek to broaden and deepen its conversation with the R&D community in mental health trusts, and develop a shared understanding of how we can collaborate better.

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The McPin Foundation is a specialist mental health research charity based in London but working across England. We exist to transform mental health research by placing lived experience at the heart of research activities and the research agenda.

### Our work includes:

- Guidance and expert support on public and patient involvement in mental health research
- Collaborative research studies in partnership with organisations interested in user focused mental health research
- Campaign and policy work to raise the profile of mental health research and improve access to evidenced based information



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