



## Invitation to Tender:

# Research on the links, connections and differences between personality disorder and autism, including challenges around diagnosis

<b>Our ambition</b>	We are commissioning research into an under-researched area because we want to move forward knowledge and understanding of complex mental health problems. We seek to support work that will contribute to how we support and care for people experiencing health problems presenting as personality disorder and / or autism. Put simply we want to see change in practice, contributing to work that addresses the substantial current concerns that help-providing systems are not doing enough.
<b>Brief description</b>	We are seeking to fund <b>original research</b> in the area of diagnostic overlap between personality disorder and autism, and the consequences of any overlap that exists. We are keen that the research we fund has a practical benefit progressing knowledge in this area and developments that benefit service users. The brief is to investigate the links between these two health experiences and differences. This focus was established through discussion and exchange with professionals and those with lived experience, and crucially as the result of a survey we carried out. We are looking to commission one or more research projects. We do not provide an explicit research question or methodology. We are interested to know from applicant research teams what they see as the important next steps given the existing body of work and how they would approach our challenge – <b>achieving a legacy for Lindsay through the commissioning of research</b> . We welcome both classical and innovative approaches and proposals. It is a requirement of the project that experts by experience are part of the research team and involved in the design of the studies. The form of research will be dictated by the approach chosen but could be a PhD project, a research project linked to a larger piece of existing work, an evaluation of a project or service or another design that fits the brief.
<b>Funding</b>	We have £80,000 to spend on commissioning research. We aim to commission at least one project, but we might fund more than one study. Thus, we encourage people to apply for smaller grants as well as for all our available resource. We also encourage

	matched funding for a PhD studentship award but also other awards as well. A further £20,000 will be available for the dissemination of the project findings. This money is “ring fenced” specifically for service user led dissemination and will be commissioned separately.
<b>Who is eligible to Apply</b>	Research Project(s): Anyone can apply who has the skills and experience to deliver the research brief with a study that meets the outlined criteria. This includes established and early career academics within Universities, voluntary sector-based research staff, and independent researchers.
<b>Deadlines</b>	Applications to be received <b>by Friday 29<sup>th</sup> May 2020</b> send to: <a href="mailto:contact@mcpin.org">contact@mcpin.org</a> Award allocation will be by September 2020. Projects to start by January 2021 for projects, and PhD’s by October 2021.
<b>Tender contact</b>	We can answer queries related to this call. Our email box is not reviewed daily so please allow us time to reply: <a href="mailto:contact@wordsthatcarryon.org">contact@wordsthatcarryon.org</a>

## About Words That Carry On

**Words That Carry On** is a fund dedicated to investing in mental health research. It has been set up in memory of Lindsay Riddoch, an ardent advocate for better mental health services who was intent on ensuring people who lived with mental health problems had their voices heard.

Lindsay struggled with mental health issues over an extended period and spent the last eighteen months of her life in closed institutions. The ongoing experience made her a powerful and effective advocate of better mental health provision and all that implies. We want to commission research in order to improve understanding, treatments and supports so that better provision and support can be provided.

The fund is managed by Lindsay’s family and friends with the support and experience of the McPin Foundation which hosts the fund for us. You can read more about us at: [www.wordsthatcarryon.org](http://www.wordsthatcarryon.org)

*Fiona Riddoch*

## Background

We encourage potential applicants to read our [scoping report](#) which is the result of a survey and interviews to help us refine what research to commission in this call. We also held a workshop with practitioners, people with personal experience of personality disorder and/or autism to provide us with further guidance which has led to ring fencing funds for dissemination led by lived experience researchers and trainers.

Personality disorder and autism, and the links as well as the divergence between these two complex health problems, are very under researched areas and we want to prioritise this research gap as the focus for the first Words That Carry On research commission. And this is all within the context of concerns about labels, and the words used to describe complex health problems. In this document we have used two specific terms, but we recognise the controversial and contested nature of the label personality disorder. We are interested in work drawing on different frameworks as well as these diagnostic categories. We have heard about and concluded:

- There is very little research that has looked at the diagnostic overlap between personality disorder and autism. Progressing work in this area will require exploration to understand the biological, psychological and social factors that influence poor health, the course of health problems and their impact. These impacts relate to those affecting individuals and their families, friends as well as communities, and at a population level our society. The cost of poor mental health runs into billions of pounds per year due to lost life opportunities as well as use of healthcare services. Or too often lack of adequate health care provision with limited treatments and support on offer.
- This topic is viewed as important by people with mental health problems, families and carers, practitioners, policy makers as the diagnostic process, and all its imperfections, are vital in the care pathway when seeking information about, understanding and treatment / support for complex health problems. The value of the involvement of experts by experience defining structuring and conducting research and co-production of information is central to WTCO thinking.
- There are lots of unanswered questions raised during our scoping work including why do we have such large gender differences in diagnosis in personality disorder and autism?
- Current provision of support for people diagnosed with personality disorder, who may also present with problems that might relate to autism, and visa versa is seriously lacking. There is very little training for staff in understanding the overlap in these two health conditions on the ground and managing complexity. The user community is actively challenging the current models of training and information delivery for professionals within the service. Communication seems to be poor at every level hindering service deliver, user-led decision making, involvement of family members, development of new innovations and support.
- There is a lack of innovation across the research sector addressing personality disorder and autism. We need people with talent and creativity, energy and innovative ideas to take forward the research agenda and produce knowledge that can lead to changings in people's lives (service user, family /carer, practitioner).



Feedback from our stakeholder event September 2019.

## Research brief

We are particularly interested in the overlap between personality disorder and autism and look to the research, practitioner and experts by experience communities to recommend what projects should be carried out. The research once complete will progress understanding, and its findings will be disseminated in a program informed and led by experts by experience (to be commissioned separately).

A few things to bear in mind:

- Our resources are limited, we have a total of £80,000 to spend to commissioning research. If you can match fund, that would be viewed favourably.
- We want work to complete within 24 months of grant start date for research projects and 4 years for a PhD studentship.
- It is a requirement of the project that individuals with lived experience of personality disorder and / or autism are involved in this research. The research idea, application for funding as well as delivering their project idea, must be co-produced with experts by experience and this must be demonstrated in the proposal and budget. We are interested in peer research methods, and peer leadership as well as more mainstream models of PPI ([patient and public involvement](#)) and [co-production](#). There must be a relevant expert by experience member of the applicant team.
- Applicant teams must include members with a track record of working in these fields, demonstrating a clear interest in personality disorder and autism. This may mean people working with new collaborators and partners in order to cover both specialisms.

- We encourage applications which test innovative and different thinking from within the context of established expertise.
- We are not specifying what research methods should be used. We want applicants to justify the methods they choose. We are interested in the use of ‘big data’ and mixed method studies that include qualitative research and peer research.
- We would like applicants to demonstrate how their work might link with other studies, or policy work in this area. How will your proposal lead to changes in our understanding and or the experience of care for people with complex mental health problems.
- We would like the application to propose how the findings of the research will be presented in such a way as to be easily adopted into existing training activities for professionals, or into ongoing best practise processes within the NHS. Outcomes must include actionable information and guidelines. This is the case for an epidemiology study as well as health services research – we want to see how the research can help people in practice better understand and work with personality disorder and autism.

## Structure of your application

We are looking for the following headings in your funding application:

- **Plain English Summary.** Maximum of 300 words describing the project.
- **Who is in your team?** List all applicant team members, their expertise and planned roles.
- **What we know so far?** Introduction and backgrounds section with references.
- **Why this research is needed?** What is the rationale for the piece of work you are proposing and what might be the pathway to impact? We want to know why this project, why now and what you hope to achieve to benefit service users, families and staff affected by personality disorder and / or autism.
- **Your project proposal.** We are looking for the following sections - aims, method, ethical considerations, analysis strategy, involving experts by experience and working alongside service users, team expertise (and how this work fits with other ongoing or planned research), team management plan, dissemination.
- **Timetable.** A month by month breakdown of tasks.
- **Budget.** We require a detailed budget separate plan and justification.
- **CVs.** We are looking for short CVs of lead applicant and any other named individuals who are part of project team with a significant role in the project.

Your application should be no longer than 8 pages plus CVs.

## Eligible Costs for projects

- Research staff time of those working directly on the project;
- The time of advisors and collaborators with direct and relevant personal experience (experts by experience, service users and family members);
- Consumables: travel using sustainable means, advisory board meeting costs;
- Other direct research costs such as transcription, participant vouchers;
- PhD stipend and course fees.

## Ineligible Costs for projects

- Staff with existing salaries through funded posts within an organisation (this is likely to be senior staff who supervise the study);
- General IT equipment and capital goods;
- Indirect/ estate costs and all other overheads;
- Conference attendance;
- Open peer view subscription costs.

## Our selection criteria

We will look at all applications and score them using the criteria below, sending the highest scoring to our advisory board for consideration. We plan to also involve peer review for short-listed applications and we may interview teams as part of our final decision making process.

<b>APPLICATION SCORING: INITIAL REVIEW STAGE ONE</b>
<ul style="list-style-type: none"><li>• Research idea and quality of the application</li></ul>
<ul style="list-style-type: none"><li>• Experience and expertise of the team</li></ul>
<ul style="list-style-type: none"><li>• Lived experience expertise (and other relevant stakeholder involvement)</li></ul>
<ul style="list-style-type: none"><li>• Pathways to impact – what might this project add to current knowledge base</li></ul>
<ul style="list-style-type: none"><li>• Value for money</li></ul>
<b>APPLICATION REVIEW: STAGE TWO</b>
<ul style="list-style-type: none"><li>• Plain English summaries will be sent to advisory panel for review</li></ul>
<ul style="list-style-type: none"><li>• Highest scoring proposals will be sent to peer review (this forms the short list) considering scientific merit of proposal, feasibility of plans, expert by experience input, and pathway to impact</li></ul>
<b>APPLICATION REVIEW: STAGE THREE</b>
<ul style="list-style-type: none"><li>• Peer review feedback collated on short list</li></ul>
<ul style="list-style-type: none"><li>• Panel members sent all scores and applications to consider</li></ul>
<ul style="list-style-type: none"><li>• Advisory panel meeting, possibly including interviews with applicants</li></ul>
<ul style="list-style-type: none"><li>• Advisory group make funding recommendations, final decision taken on awards. This may involve an interview; this is to be decided by the panel during the process.</li></ul>

Please send your application to: [contact@mcpin.org](mailto:contact@mcpin.org) by 29<sup>th</sup> May 2020.