McPin Foundation
Transforming mental health research

RIGHT PEOPLE, RIGHT QUESTIONS

Research Priorities for Children and Young People's Mental Health:
Interventions and Services

CONTENTS

For more information about the individual questions, see the supplement 'Focus on the Questions'.

A word about wording In this report, we have kept as close as possible to the phrasing of priorities provided by people submitting the original questions. This means several terms are used interchangeably to describe mental health conditions, including "mental health issues", "problems" and "difficulties".

WHO WAS INVOLVED?

Young People's Advisory Group

Amelia, Eva, Katy, Kymani, Lucy, Mary and Syinat

Steering Group

Co-funders

Clair Chilvers, Mental Health Research UK; Sophie Dix, MQ; Clare Stafford, The Charlie Waller Memorial Trust; Hamish Elvidge, The Matthew Elvidge Trust

Other stakeholders

Cornelius Ani, member of the Faculty of Child & Adolescent Psychiatry, Royal College of Psychiatrists

Ruth Atkins, parent

Rachel Churchill, Professor in Evidence Synthesis, University of York

Charity Gondwe, parent

Nick Heard, teacher

Nushra Mansuri, Senior Lecturer in Social Work, Coventry University

Wayne Reid, Professional Officer, British Association of Social Workers, England

Steven Pryjmachuk, Professor of Mental Health Nursing, University of Manchester

Maryrose Tarpey, Independent Advisor, James Lind Alliance

André Tomlin, Managing Director, Minervation Ltd

The McPin Foundation

Lauren Evans, Senior Researcher and Project Co-ordinator for Right People, Right Questions

Naomi Clewett, former Senior Researcher and Project Co-ordinator for Right People, Right Questions

Thomas Kabir, Public Involvement in Research Manager, and Project Lead for Right People, Right Questions

Rachel Temple, Researcher and Co-coordinator of the Young People's Advisory Group

Humma Andleeb, Researcher and Co-coordinator of the Young People's Advisory Group

Jessica Bond, freelance journalist

Vanessa Pinfold, Co-founder and Research Director

The James Lind Alliance is an independent, non-profit-making initiative. It brings patients, carers and clinicians together in Priority Setting Partnerships to identify and prioritise the Top 10 uncertainties, or unanswered questions, about health conditions and the effects of treatments. For more information, visit **jla.nihr.ac.uk**

FOREWORDS

YOUNG PEOPLE'S ADVISORY GROUP

Being involved with drawing up the list of the most important unanswered questions for young people's mental health has been an exhilarating experience. We have all contributed our own experiences and learned new skills. We were encouraged to be creative, and to laugh a lot as well.

We are experts by experience and we are proud to have had the opportunity to give young people's perspectives into the shaping of future research. Our involvement means that the results are relevant to young people's lives and reflect their concerns. It sends a message that young people's views should be acknowledged and respected.

We should be involved in these types of decisions – including how to spend public money to improve children and young people's mental health. This project is the first step to getting answers that can lead to young people being better supported.

STEERING GROUP

The mental health of children and young people is of paramount importance to society. Maintaining good mental health in young people and boosting their resilience will help them throughout their lives.

Not enough is known about young people's mental health. The unanswered research questions presented in this report are the result of a process that has involved many stakeholders. Importantly, these include children and young people, and the people who support them, whether as parents, teachers or clinical staff. What they say matters.

Many of the questions raised in this project are broad and they will need to be refined and made more specific so that they can be answered by research. We now have an obligation to provide answers.

VANESSA PINFOLD, THE MCPIN FOUNDATION

This project was developed because whilst attention to children's and young people's mental health has been steadily growing in recent years, the research community has yet to respond in any significant way. This is beginning to change.

We hope *Right People, Right Questions* can feed into this momentum, with our findings arriving at a useful time. We know spending on mental health research is low,[1] but it has been good to hear in the responses by funders to this report that many have plans for supporting research into the mental health of young people and hopefully involving them in the research process. What was particularly striking within the *Right People, Right Questions* process was how many submitted questions do have answers, but these are generally unknown outside academic circles. We need to find a way to make research findings far more accessible and useful.

Finally, I was particularly interested in question 11 which was narrowly left out of the Top 10; the cultural appropriateness of interventions and treatment solutions must not be forgotten. I urge you to digest all 25 questions presented in our reports, and reflect on how your own work and practice can contribute to providing fresh answers.

THANK YOU

This project would not have been possible without the help of a large number of people. We want to acknowledge the support from our funding partners and the James Lind Alliance for guiding us through the priority-setting process. We are grateful to everyone who filled in the surveys and to all our supporters who spread the word and helped us get such good cross-sector engagement.

Thank you to the people who attended the workshop and to Orygen, a youth mental health organisation based in Melbourne, Australia, which shared its research database with us. Finally, a huge shout out to the members of the steering group and the Young People's Advisory Group who made sure we completed this project and learned a lot from each other along the way.

THE TOP 10 PRIORITIES

1 Would the screening of young people be appropriate for the early identification of mental health difficulties, and if so, what would be the best way of carrying this out?

2 How can young people be more involved in making decisions about their mental health treatment?

3 How can Child and Adolescent Mental Health Services (CAMHS), education providers and health and social care departments work together in a more effective manner in order to improve the mental health outcomes of children and young people?

4 What are the most effective early interventions or early intervention strategies for supporting children and young people to improve mental resilience?

5 What interventions are effective in supporting young people on Child and Adolescent Mental Health Services (CAMHS) waiting lists, to prevent further deterioration of their mental health?

6 What methods can parents use to identify that a child or young person's mental health is deteriorating?

7 Which interventions are effective at supporting suicidal young people?

8 How do family relationships, parental attitudes to mental health, and parenting style affect the treatment outcomes of children and young people with mental health problems (both positively and negatively)?

9 What are the most effective self-help and self-management resources, approaches or techniques available for children and young people with mental health issues?

10 What is the most effective way of training teachers and other staff in schools and colleges to detect early signs of mental health difficulties in children and young people?

NOTES

1. These questions need to be considered in light of the question ranked 11th in the list: How can the number of effective culturally appropriate approaches available in children and young people's mental health services be increased, particularly for ethnic minority groups?

2. Although there will no doubt be a digital component to the answers of some of the questions, we ruled out questions from the public specifically about digital technologies because they were the subject of another recent priority-setting exercise.[2]
Please see mindtech.org.uk/research/digitalmhq

WHY DID WE DO THIS WORK?

Childhood and adolescence are crucial times when it comes to people's mental health. We know that most adults supported by mental health services had problems that emerged in childhood.[3] This is commonly reported as half of all mental health difficulties manifest by the age of 14, with 75% by age 24.[4]

The situation in the UK is that:

- 1 in 8 children and young people aged between five and 19 had a diagnosable mental health difficulty in England in 2017. For young women aged 17 to 19 the rate was 1 in 4, with over 50% identifying as having a mental health problem also reporting to have self-harmed or made a suicide attempt[5]

- Rates of self-harm among young people are on the increase and are starting at a younger age[6]

- Adverse childhood experiences impact on health outcomes including mental health[7]

- Having a mental health difficulty in childhood is known to have long-term consequences for educational attainment and employment opportunities[8]

- Suicide was the leading cause of death among children and young people over 10 years old in England in 2015.[9]

Services are struggling to meet this need:

- Access to mental health support is in short supply for children and young people, with the NSPCC reporting in 2018 that only 12% of clinical commissioning groups have adequate plans to cover the need in their local community[10]

- A 2015 report by Public Health England acknowledged that around 70% of children and adolescents have not had appropriate interventions at a sufficiently early age[11]

- In 2016, a survey of mental health professionals found that 70% felt that services offered to children are inadequate or worse[12]

- A recent survey of 2000 parents and carers found that 76% thought their child's mental health had deteriorated while waiting to access Child and Adolescent Mental Health Services (CAMHS).[13]

Taken together, these findings make a compelling case for the need for change. Now is the time to act. Children and young people's mental health is high on the UK Government's agenda, with the recent publication of a green paper[14] and a commitment to produce an annual "state of the nation" report in 2019.[15] There is also real momentum within the mental health research community to make things better.

But what should this change look like? At the McPin Foundation, we believe that high quality research and evaluation is part of the answer. We need change that is based on evidence that demonstrates what works. That evidence can be generated using different methodological approaches, working with researchers across varied disciplines and produced using creative as well as traditional media.

We know resources for mental health research are scarce so we need to make sure that what we do have is used effectively. We believe that investments are best used when they can answer the questions that matter most to the people that the research has the potential to affect – in this case, children and young people. One way of ensuring this happens is to get children and young people involved in the research prioritisation process, something that has been identified as a priority for the sector over the coming decade.[16]

With this project, we wanted to find out what questions children and young people, and those who support them, want researchers to answer about mental health. We wanted to enable them to have a say in identifying important gaps in understanding and, consequently, have an opportunity to influence what research gets funded in future. The topic under consideration is a large one. Our advisory groups helped us to focus our efforts and together we decided to look at questions related to interventions and services.

The result is a list of the most pressing, unanswered questions about interventions and services to support children and young people's mental health. It is the first time, to our knowledge, that such a list has been produced across the world in this way by young people and others involved in supporting them. We hope that it will shape the agendas of researchers, research funders and policymakers in the next three years. Ultimately, we hope that it will lead to a real difference in the lives of children and young people everywhere.

YOUR OTHER PRIORITIES

11 How can the number of effective culturally appropriate approaches available in children and young people's mental health services be increased, particularly for ethnic minority groups?

12 What role does having a healthy lifestyle (e.g. sleep, diet, and exercise) play in the prevention of mental health problems in children and young people?

13 What are the most effective interventions for managing and reducing harmful stress in children?

14 Do young people who receive a prompt psychiatric diagnosis experience better mental health outcomes than those who wait longer to receive a diagnosis?

15 What methods are effective at supporting young men to recognise the signs of mental ill health and access appropriate support? (E.g. stigma reduction)

16 At what ages would it be most effective to start to educate children and young people about mental health?

17 In what way do children and young people (11-25 years) feel that their mental health condition could have been prevented?

HOW DID WE GET TO THE TOP 10?

To identify the Top 10 most pressing, unanswered questions about children and young people's mental health, we convened a Young People's Advisory Group and a steering group. Guided by the James Lind Alliance, together we went through an inclusive and thorough priority-setting process.

DECEMBER 2016

INVOLVING THE RIGHT PEOPLE

A group of funders and supporters was assembled to guide the project, alongside young people, parents and representatives from teaching, social work, mental health services and the charitable sector. They became the steering group for the project.

A Young People's Advisory Group was set up and included seven people aged 14 to 23 who were passionate about mental health research. These two groups were central to all aspects of the project.

JULY TO OCTOBER 2017

GATHERING YOUR QUESTIONS

A survey was designed to gather the public's questions about young people's mental health. **2,566 PEOPLE** submitted over **5,500 QUESTIONS**. Respondents described themselves as:

40% Young people (under 26)

40% Parents

12% Teachers or school-based support staff

4% Psychologists or psychiatrists

9% Mental health nurses, therapists, or other support roles*

61% female   **34%** male   **2%** non-binary

3% didn't say or said they identified as a gender that wasn't listed.

48% acknowledged they had **experienced mental health difficulties** themselves.

JULY 2018

* People could choose more than one option. Not everyone provided demographic information and we have based these calculations on those who did.

NOVEMBER 2017 TO JUNE 2018

SORTING AND REDUCING YOUR QUESTIONS

With so many questions submitted, we decided to sort them into themes and take forward the largest theme. This was **Interventions & Services**. It included 3,000 questions, many of which overlapped with the other themes.

WE WHITTLED THESE QUESTIONS DOWN TO 91.

3,000 QUESTIONS

We ruled out any that were out of scope, ambiguous or too broad.

650 QUESTIONS

We grouped similar questions together and came up with one overarching question that captured their meaning.

210 QUESTIONS

We checked the existing research to see how many had already been answered.

91 QUESTIONS

We were left with a large group of questions that had not already been adequately answered by research.

JUNE 2018

PRIORITISING YOUR QUESTIONS

A second survey asked the public to pick which of the 91 questions they felt should be prioritised. Since including all 91 would have meant an extremely long survey, we used software to show each person a random selection of 40 questions and asked them to choose 10. The software then combined everyone's responses and we generated the top 25 questions to consider.

753 PEOPLE TOOK PART

THE FUTURE

The next step is to get answers to the research priorities and use them to shape policy and practice.

PICKING THE TOP 10

The 25 final questions were discussed and prioritised in a workshop attended by members of the Young People's Advisory Group and steering group, as well as young people, parents and professionals who were new to the project. By the end of the day we had agreed on and ranked the **10 MOST IMPORTANT QUESTIONS**, within the theme of Interventions & Services, for children and young people's mental health.

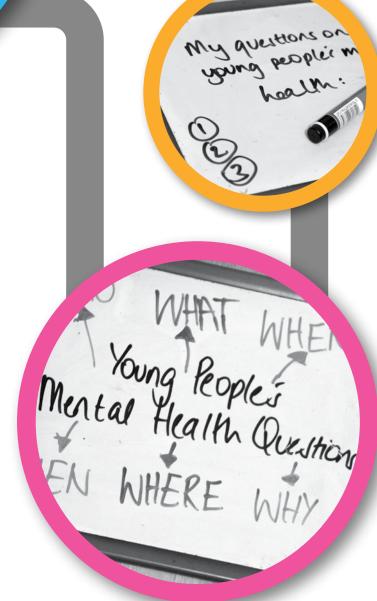# HOW DO YOU KNOW THESE ARE THE TRUE VIEWS OF THE PEOPLE WHO MATTER?

We tried to be as inclusive as possible. People could respond online or return a paper copy of the survey. We spent many months building relationships with organisations and individuals that work with marginalised or disadvantaged communities. This helped us to disseminate our surveys widely.

We worked closely with our Young People's Advisory Group to ensure we got responses from young people. We also monitored who was responding and saw that we needed to work harder to attract males and those working in the education sector.

HOW DID YOU PICK THE TOP 10 QUESTIONS OUT OF THE 25 PRESENTED IN THE WORKSHOP?

The attendees were split into three groups. To ensure a balance of perspectives, each group contained at least two young people and one parent, as well as a mix of psychologists, psychiatrists, inpatient support staff, teachers, teaching support staff, social workers, and representatives from the charity sector.

The three groups ranked the 25 questions. The ranks from all the groups were combined to come up with a final list, using a process known as the Delphi method. Everyone then had a chance to discuss the order and make any final changes.

HOW EXACTLY WERE THE YOUNG PEOPLE INVOLVED?

The Young People's Advisory Group was involved at all stages of the project. From choosing the name *Right People, Right Questions* and designing the logo, to developing the surveys, making a video to encourage young people to respond, thematising the questions and deciding which theme to take forward.

They provided input into the structure and content of the reports. Two members of the group were present at every steering group meeting and no decision could be passed without their agreement.

WHAT DOES "UNANSWERED BY RESEARCH" REALLY MEAN?

Guided by independent information specialists, we searched the existing research to see if there was any recent and good-quality evidence that answered the questions that were submitted. Based on this, we categorised each question according to its answer's level of uncertainty. For more information, see page 4 of the supplement 'Focus on the Questions'.

YOUR OTHER PRIORITIES

18 Which school-based interventions are most effective at promoting and developing emotional wellbeing in children and young people?

19 Which school-based interventions are most effective in building mental health resilience in children and young people?

20 Are children from low income households waiting longer to access mental health services than children from financially better off households?

21 What impact does a longer waiting time for mental health services have on the treatment and mental health outcomes of children and young people with mental health difficulties?

22 How can early intervention prevent the development of mental health problems in children and young people with an autistic spectrum disorder or learning difficulty?

23 How can homeless young people be supported with their mental health needs?

24 Which interventions or methods are effective for young people to cope with panic attacks?

25 How can parents identify and support children who are at risk of suicide without increasing the child's level of distress?

WHAT NEEDS TO HAPPEN NOW?

THE TOP 10 QUESTIONS REPRESENT BROAD AREAS WITHIN CHILDREN AND YOUNG PEOPLE'S MENTAL HEALTH WHERE MORE RESEARCH IS NEEDED.

WE CALL ON:

Research funders to provide resources to fund research questions that address these priorities

Researchers and research institutes to commit to building an evidence base around the priorities, answering specific research questions and including young people in the design, delivery and dissemination phases

Policymakers to use the answers to these questions to formulate policy that leads to meaningful change

Young people, their supporters and our project partners to keep the spotlight on these questions and get involved in research projects that take our understanding on these topics forward

IN RETURN, MCPIN COMMITS TO:

- Work with our project partners and funders to get these questions answered

- Encourage dialogue between researchers, funders and our partners, and children, young people and their supporters

- Get involved in new research projects related to children and young people's mental health

- Facilitate the involvement of children and young people in research that has the potential to affect them

- Make all the questions from the initial survey available, and point out which have already been answered by research

YOUNG PEOPLE'S INVOLVEMENT: WE'VE ONLY JUST BEGUN

Although the consultation is finished, there is still plenty for the Young People's Advisory Group to do. For example, in the first public survey, many people submitted questions that have already been answered by research. Over the next couple of months, the young people will produce a document that uses this existing research to respond to and publicise the answers to these questions. A larger Young Person's Network will also be set up and will be involved with any future work related to children and young people that the McPin Foundation contributes to.

FUNDERS RESPOND

"It is clear that a radical new approach is needed to drive forward mental health research, and to improve treatments for people with mental health problems. The Wellcome Trust has agreed to renew our focus on mental health over the next decade, with emphasis on improving outcomes for young people with depression and anxiety. To do this, it is critical that our work involves young people with lived experience of mental health problems."
Louise Marshall, Wellcome Trust

"MQ welcomes this important report. We have been delighted to be a partner and co-funder. The good news is that momentum is truly building in the area and a number of significant research initiatives are underway. For example, at MQ, our IDEA project is helping to tackle the first question, working to define risk factors for depression in young people and supporting the development of a screening tool. This project gives us all a focus to ensure the right questions are answered. We'll be using the priorities to guide our future funding." Sophie Dix, MQ

"Mental health is a strategic priority for the Economic and Social Research Council and we are currently committed to supporting research in this area. We are interested in a life-course approach to mental health research, whilst recognising the importance of the early years, and consequently consider this report to be extremely valuable." Wendy Matcham, Economic and Social Research Council

"The Medical Research Council has made understanding how and why mental health problems develop in young people, and how we might better intervene early on, central to our research strategy for mental health. It's important that mental health research is informed by the questions that are meaningful to young people. The questions set out in this priority-setting exercise reflect the breadth of research that would make a real difference in their care and experience of mental health problems."
Rachael Panizzo, Medical Research Council

"We were pleased to be a funding partner in this work, supporting our commitment to research on children and young people's mental health. We continue to fund PhDs in this area and have seen an increase in both the number and quality of applications in recent years. The Top 10 will be useful to us as we consider which children and young people's scholarship to award in 2019."
Clair Chilvers, Mental Health Research UK

STAY IN TOUCH, GET INVOLVED

IF YOU ARE A RESEARCHER…

Please keep us informed of any research inspired by the Top 10 questions by emailing contact@mcpin.org. Let us know if you would like the Young People's Network to consult on and help shape your research proposal.

IF YOU ARE A YOUNG PERSON…

Join the Young Person's Network and receive emails about research involvement opportunities. Sign up by going to mcpin.org/young-people/

IF YOU ARE LOOKING FOR PARTNERS…

Connect with us using contact@mcpin.org to see how we could work together.

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ABOUT THE MCPIN FOUNDATION

We are a mental health research charity. We champion experts by experience in research so that people's mental health is improved in communities everywhere.

- We deliver high-quality, user-focused mental health research and evaluations

- We support and help to shape the research of others, often advising on patient and public involvement strategies

- We work to ensure research achieves positive change

Research matters because we need to know a lot more about what works to improve the lives of people with mental health difficulties, their families and communities. We believe better mental health research is done by involving experts by experience. We work collaboratively with others sharing our values.

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RIGHT PEOPLE, RIGHT QUESTIONS

RESEARCH INTO YOUNG PEOPLE'S MENTAL HEALTH