MQ

Transforming mental health through research

2018

Young People's Mental Health Research – Towards a Brighter Future

MQ Policy Report

Introduction

1 in 4 of us experience mental illness in any given year[1] **and 75% of adult mental health problems begin before the age of 18**[2]**.** The most recent surveys of child and adolescent mental health have shown that in an average school classroom of 30 young people, three will have a diagnosable mental health condition[3].

Despite the number of people affected and the huge unmet need, the sad truth is that not enough is spent on mental health research. To date, there is a lack of parity when it comes to funding mental health research with only 6% of the overall research budget being spent on it. Only a proportion of this funding (30%) is spent on research with young people[4].

Developing a mental health condition whilst young can have a devastating impact on education, employment opportunities and physical health as well as the ability to form meaningful relationships. With mental health costing the UK economy £105 billion a year, this is a situation we cannot afford to ignore[5].

In our MQ young people's manifesto[6], we pledged to invest in a world leading programme of research called *Brighter Futures*.

The three goals of Brighter Futures

1

Understand how mental illnesses develop

2

Identify which young people are most at risk

3

Develop more effective ways to help

Our Brighter Futures Programmes

Identifying Depression Early in Adolesence (IDEA)

Depression affects about one in five people around the world during their lifetime - yet we still lack the ability to identify which young people are most likely to be affected. MQ's IDEA project plans to identify universal risk factors for depression in young people by analysing research and data about social and family environment, stressful experiences, brain images, and biological data of 10-24 year olds from the UK, Brazil, Nigeria, and Nepal. Using this data, their aim is to develop a screening tool to better identify young people at risk and enable support to be provided sooner.

Help Overcome and Predict the Emergence of Suicide (HOPES)

Suicide is the leading cause of death for young men and women worldwide. MQ's HOPES project aims to develop a global model to identify people who are most likely to try and take their own lives. Analysing brain scans, and psychological and social data on suicidal behaviour and traits of young people from across the world, the team aim to develop a tool that will not only help practitioners identify young people at risk, but help them to provide the most effective support when people are struggling.

The MQ Adolescent Data Platform

The MQ Adolescent Data Platform for Mental Health Research, hosted at Swansea University Medical School's SAIL Databank, will anonymously bring together a large range of existing and new information relating to the mental health of young people aged 10-24 from across the UK. This will provide an unprecedented resource for researchers and policy-makers to improve understanding of mental illness in young people, address historical service challenges, and tackle inequalities in mental health.

The recently published Government's Mental Health Research Framework[7] sets out a collective vision of where we can make significant gains over the next 10 years in progressing mental health research, particularly for children and young people.

Within days of the Framework being published, the Children and Young People's Green Paper for England[8] was also published, with commitments to commission research into interventions to support families and carers.

Research priorities identified in the Mental Health Research Framework must be acted on. They must also form part of the wider agenda for children and young people's mental health. Now is the critical time for us all to work together and meet the scale and ambition of the tasks ahead.

Research – helping us to understand our world and make our lives better

Research helps us to understand our world - it grows out of our primary human need to learn and acquire knowledge, to solve problems and gain a wider perspective about our world. In health, furthering knowledge through research helps us to create effective interventions and can save lives.

At MQ we bring researchers from different disciplines together to advance our understanding of mental health. Mental health research incorporates a variety of disciplines - biological, psychological, medical, social, and environmental because the reasons *why* people experience poor mental health are complex and often intertwined. For example:

Environmental - large cohort studies have highlighted the impact of adverse childhood experiences on the increased risk of developing mental health conditions in adulthood[9 10].

Social determinants - housing, poverty, unemployment (or poor employment) and education have an impact on our health, including our mental health[11].

Biology, genes and hormones - we need to develop greater knowledge and awareness of the hormonal changes that young people experience through puberty and how genes impact on brain functioning, brain plasticity and emotional well-being.

Determinants of mental health inequalities - certain population groups, for example, lesbian gay bisexual and transgender, the prison population and some Black Asian minority ethnic communities are at higher risk of developing mental health problems.

A life course approach helps us to address critical periods of development such as childhood and adolescence – it is particularly valuable in mental health research as the wider determinants of mental health problems are so diverse. As stated in the Research Framework[12], young people must be a priority group within the research community because it is an important time for development and growth.

Young people's mental health research and the **UK policy context**

UK mental health policy

Mental health is rising up the policy agenda at pace across the UK with key priorities including prevention, early intervention, parity with physical health (now enshrined in legislation) and the need to support children and young people. We need long term policy plans that are bold and meet the scale and challenge of young people's mental health - see appendix one for more details of children and young people's policy in different parts of the UK.

Putting research at the heart of UK mental health policy

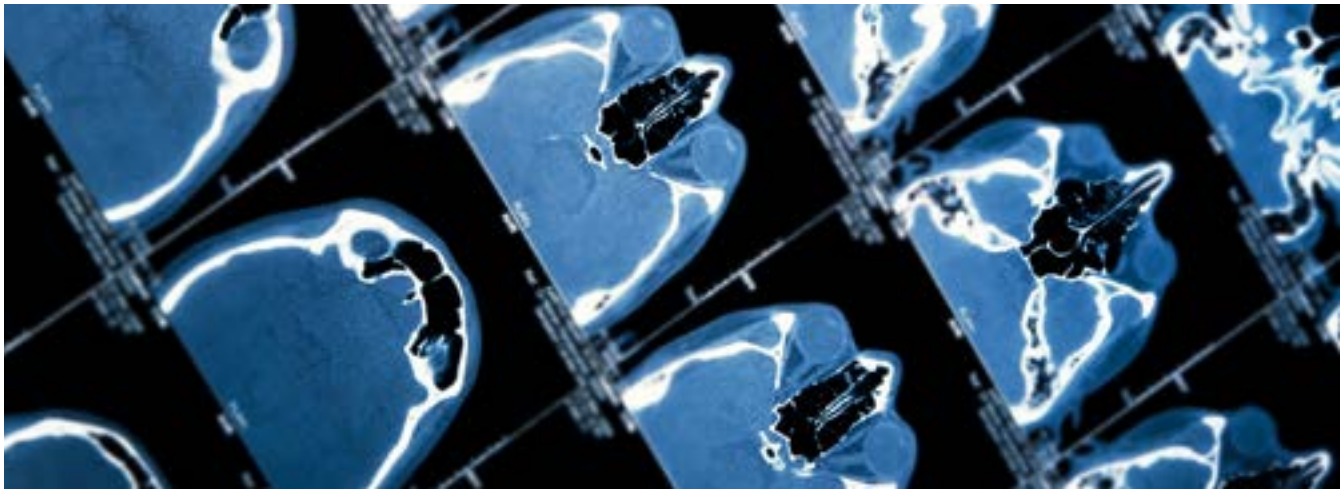
Whilst mental health policy that focussed on children and young people has broadly gained ground across the UK, it's fair to say that mental health research has not been integral to the policy agenda. The consequences of this are born out of the lack of attention to mental health research overall - from research funding (both public and government investment) to evidencing new interventions and treatments in mental health.

Research policy developments

The recently published 10-year Framework for Mental Health Research sets out a collective view of how mental health research should move forward in the UK, and how implementation of research evidence can be accelerated to drive progress. Recommendations are: 1. taking a life course approach to mental health research; 2. systematically embedding patient and public involvement in mental health research, in particular advancing the involvement of children and young people; 3. strengthening the connections between physical and mental health; 4. greater co-ordination and leadership of mental health research activity, with greater integration between the different research disciplines; 5. improved data informatics and virtual populations 6. flexible funding arrangements and 7. promoting research in alternative settings, such as families and schools[13].

UK research developments are largely informed by policy and strategy that is set out by mental health research funders and the research councils. The recently published strategy by the Medical Research Council (MRC) *Strategy for Lifelong Mental Health Research* (April 2017) aimed to accelerate understanding of mental illness and pledged to work with partners across the four nations of the UK to expediate this. In August 2017, the research councils developed their cross-disciplinary agenda to articulate opportunities for working together in mental health.

At a European level, an important development on mental health research was provided by ROAMER in Europe. ROAMER was funded by the European Commission to create a coordinated road map for the promotion and integration of mental health and well-being research across Europe. ROAMER involved over 1,000 people and organisations in developing their priorities (which included children and young people) and concluded that there was an urgent need to co-ordinate research efforts across Europe as mental health research is lagging other disciplines[14]. ROAMER has influenced the developing mental health research strategy in England as well as work in the EU, and driven significant new research initiatives.



Priorities for **action**

At MQ we want to ensure that mental health research and young people are kept on the policy agenda, so we have drawn up key policy areas that we developed and believe should be prioritised by the governments across the UK. Tackling these key areas could make a huge difference to young people's mental health.

1

The need to make mental health research funding a national priority – improvements and investment in mental health research funding needs to be prioritised across the UK and young people should be a priority group for research funders.

2

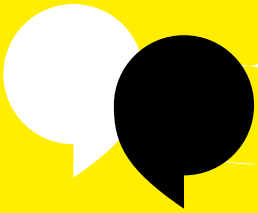
Improved data and improved access to data – researchers rely on access to good quality data to further their research and inquiry.

3

Involving young people in research – we want to see young people more meaningfully involved in actively shaping research; from inception and planning to research and dissemination.

4

Support interventions and research in 'real world' settings – we need to advance our knowledge base of support and interventions that are happening, or could happen, in real world settings. We support the Government's ambition to prioritise advancing research in this area with appropriate, targeted funding.



The need to make mental health research funding **a national priority**

UK funding in context

The total cost of lost productivity and human suffering due to mental illness, is staggeringly high at an estimated £105 billion a year[15]. Yet, on average, the UK invests approximately 5.8% of the UK research budget on mental health. Investment in cancer research is nearly four times higher at 19.6%[16]. Or to put it another way, we spend £8 per person affected by mental health problems, 22 times less than the equivalent for cancer (£178 per person) and 14 times less than dementia (£110 per person)[17]. Given that 1 in 4 adults will experience mental health problems in any given year[18], this level of funding clearly does not match the number of those affected by mental health problems.

Research spend on children and young people's mental health is not prioritised, with less than 30% of the overall research money (£26 million a year) put towards children and young people's mental health research[19]. As a result, most of mental healthcare resources are not designed and developed with young people in mind. Very little is known about the causes of mental health problems and what interventions and support are most effective, or what could be done to prevent mental health problems from starting in the first place.

Why the low investment?

There are many possible explanations for the low investment in mental health research. Mental health research incorporates many disciplines (psychology, psychiatry, neuroscience and social sciences) and it's been suggested that the research sector has not yet integrated enough to address mental health[20]. Along the same lines, mental health and physical health research is not linked up in the way it should be and there is a lack of recognition that mental health is also key to successful outcomes in chronic physical illness (such as chronic pain). Others have pointed to the stigma of mental illness itself, contributing to levels of commitment to mental health research funding in the same way that it impacts on other decisions about mental health spend; with more money and time being spent on science in other areas.

Return on investment

For every pound spent on mental health research in the UK, the yearly recurring return is estimated to be £0.37, which is similar to the return on investment for research on cardiovascular disease[21] - so investing in mental health research will not only give us health gains, but can also impact positively on GDP.

Charitable investment

Charitable investment is also lagging in mental health research. For every £1 spent by the Government on mental health research, the public donates just 0.3p or 1/3 of a penny. In comparison, the equivalent charitable donation for cancer is £2.75 for every £1 the Government spends on cancer research. For heart and circulatory problems, it's £1.35[22].

Charitable funding of mental health research is very slowly increasing in the UK, but we need to see years of sustained giving to deliver the major advances in mental health research that are needed.

Sustained charitable funding for research has been instrumental in delivering improvements to healthcare but the public have never been asked to support research into mental health. Sustained political leadership and commitment to long term mental health funding for research from Government is very much needed but public engagement and investment is needed too.

MQ's commitment and recommendations

MQ continues to campaign for public and government investment in mental health research funding across the UK that matches the scale and costs of mental illness.

MQ Recommends: The Government and devolved nations across the UK must commit to a growth in mental health research funding – this growth should reflect the burden of mental illness and costs to society.

MQ Recommends: Young people must be a priority area for new investment in mental health research across the UK.

Research is reliant on **access to good quality data**

Data in context

Data has transformed many scientific breakthroughs in treating major health conditions – but its potential has not yet been achieved in mental health. This is particularly the case in young people's mental health. The 2017 Research Framework recognised this opportunity and prioritised improved data and informatics to guide the future of mental health research; linking datasets and drawing on new data platforms to identify high risk groups[23].

Prevalence and young people's mental health

Data on prevalence is critical for understanding trends in mental illness as well as planning for better service provision and treatments. Unfortunately, we are currently still relying on statistics from the UK Child and Adolescent Mental Health Survey in 2004, although a new survey will be published in 2018 (England only).

However, the recent Adult Psychiatric Morbidity Survey (APMS) showed a pressing need to pay attention to our young people: young women (16-24) emerged as a high-risk group. Women between the ages of 16 and 24 were found to be almost three times as likely (26%) to experience a common mental health problem as their male contemporaries (9%). The highest rates of self-harm were also reported by young women (16–24) in which one in four (25.7%) reported having self-harmed[24]. When the Child and Adolescent Mental Health Survey is published, we will get a clearer picture of what is happening before 16 years of age, but the adult survey suggests that we need to be intervening much earlier to support young people; as well as looking at gendered differences to how we respond.

In the Children and Young People's Green Paper for England, the Government committed to regular, up-to-date surveys (every seven years, as we do for adults) – this will lead to improved understanding of trends in prevalence and treatments of mental health problems in children and young people.

Utilising clinical data for research

Clinical data has important utility for mental health research. Data can be used to identify and recruit people to clinical trials and help to construct population cohorts. Data can also be used to assess outcome measures (how people are progressing, or not) and the efficacy and effectiveness of treatments or services themselves.

For example, the Improving Access to Psychological Therapies (IAPT) programme in England offers a unique insight into clinical outcomes because the service is committed to collecting information at each patient visit. The data is only loosely tapped into now, but affords researchers insight into patient response across the course of treatment and may help improve treatments too. This resource is unique to the NHS in England and should be cultivated for contributions it can make to mental health research more widely.

Other developments exist in the form of electronic health records for research. For example, the MRC are working with the Farr Institute of Health Informatics Research to improve large patient and research data sets through the new Health Data Research UK initiative and an investment of £37.5 million is going into establishing a multi-funder UK institute for health and biomedical informatics research[25].

Digital technologies

The digital era offers new opportunities for facilitating data collection and data sharing as well as supporting self-management and facilitating access to ongoing support in mental health. Younger people are the most frequent users of social media, mobile smart phones and online digital technology (in comparison to adults)[26] and young people are already using new technologies to support their own mental health and that of their friends. Digital technologies could potentially make research more accessible (and inclusive) to young people through their involvement.

Sharing data

Linking and sharing data between health, education, social care and housing is critical to broader insights into societal impacts of mental health problems and can help researchers understand the interconnectivities of mental and physical health. For example, within schools, linking health records to the National Pupil Database (and vice versa) could give us insights into broader societal impacts of mental health problems as the database contains information on ethnicity, income, special education needs (SEN), attendance and exclusions.

Health informatics could help us address key questions in public mental health, such as the unacceptable mortality gap between those with mental illness and the general population. It is essential therefore that new national investments in health informatics support further mental health research.

MQ's commitment and recommendations

MQ is working with SAIL Databank at Swansea University, to create the first Adolescent Data Platform for Mental Health Research. The platform will bring together a large range of existing and new information relating to the mental health of young people aged 10-24 from across the UK. It will capitalise on infrastructure support and new data linkage technologies to put the spotlight on young people's mental health

MQ Recommends: Informatics projects targeted at young people should be established and supported to expand the use and linkage of data. This would include linking datasets across health, education and social care[27].

MQ Recommends: Access to currently available national datasets should be accelerated by streamlining legal and ethical approvals[28] .

Involving young people in research

Young people are best placed to tell us what it is like to be young, they offer unique insights into their own experience. The experience of being a young person will be very different to young people today – you only have to look at the impact and pace of technological changes as well as the changing nature of community and the family structure to see that[29]. We believe that young people should be contributing their skills and experiences to all aspects of research – from planning and development of projects, to carrying out research themselves and to dissemination of mental health research. This is in line with UK Government's mental health research framework and practice health research guidance.

Young people also have rights, including the right to participate in decisions that affect them – this is enshrined in the United Nations Convention on the Rights of the Child (UNCRC) which makes it clear that human rights apply to children and young people, just as they do to adults. Participation is a *guiding principle* throughout the UNCRC, but Article 12 is specifically about participation and states that children and young people have the human right to be involved in decisions that affect them - this includes involvement in mental health research.

Involvement in research

In 1996 an organisation – People in Research - was set up in the UK to support researchers to involve 'patients and the public' in research. It is currently called INVOLVE, producing guidance and resources to support health and social care research, within the portfolio of the national Insitute of Health Reserch (NIHR). We know there are different activities that are understaken as involvement in research and some have had significant impact. For example, the research such as Strategies for Living[30], which was a user-led research programme based on in depth investigation of support and strategies from the perspective of users, can still be felt today. Strategies for Living helped to develop self-management and peer support approaches in the UK and elsewhere and highlighted the importance of relationships, especially family and friends in developing good mental health support

In mental health research in England, the first National Young People's Mental Health Advisory Group was established in January 2014 by the Clinical Research Network: Mental Health. The Group is made up of fourteen 16-24-year olds, all with experience of mental health issues or having supported someone who has. Members come from across England and have a wide range of experiences and interests.

Practical guidelines[31] outline the benefits of involving young people in research. They point out that young people can identify research issues and questions that professional researchers may miss as well as assisting researchers with language issues and wording. Young people presenting research findings can also help to change organisational culture around participation as well as alleviate professional's own anxieties about involvement. Young people themselves benefit – it can help with personal development, increased confidence and self-esteem, as well as an increased understanding of how to affect change[32].

Strengthening involvement

Young people's involvement in mental health research needs to be strengthened across the UK and we need to demonstrate the impact of involvement more fully through evidence. This should include involving young people with experience of mental health issues in governance and ethical reviews, as researchers working on studies, as well as research development and dissemination. With a number of ways in which young people might be involved in research it is important to ensure that any type of involvement is meaningful and considerate, incorporating the ability to usefully contribute to the research process[33].

MQ's commitment and recommendations

MQ is committed to involving young people in our research and research development. We are working with the McPin Foundation, the James Lind Alliance and other partners on the 'Right People, Right Questions' project which is identifying research questions that matter most to 11 - 25-year old's with experience of mental health problems (as well as their parents or carers and those who work with young people).

MQ continues to develop its involvement processes for young people, including through its young people's advisory group.

MQ has launched a new platform to promote opportunities to take part in mental health research for people of all ages – available at https://www.mqmentalhealth.org/articles/take-part-in-research

MQ Recommends: Research funders and those carrying out research must incorporate a vision and commitment to meaningful involvement of young people throughout the development, delivery, dissemination and governance of research.

Support, interventions and research in **'real world' settings**

Young people and real-world settings

Young people develop in the contexts of their families, schools and communities (including the digital community) all of which offer opportunities to support mental health and well-being and intervene early when mental health problems develop. The recently published Mental Health Research Framework acknowledges the need for more research taking place in 'real world settings' - that is a 'setting' representative of people's everyday experiences.

Innovative (and culturally relevant) support is taking place right now in real world settings – self-management and peer support approaches are good examples of this[34]. Low intensity interventions can also provide initial support for people on waiting lists. Support and interventions in communities (sometimes called Tier 0 interventions) are often provided by the voluntary sector and in many cases, signposted by primary care services. For example, in Wales there has been much development of Tier 0 interventions such as mindfulness, stress reduction and bibliotherapy via the Local Primary Mental Health Support Service (or LPMHSS)[35].

Developing effective interventions for young people (and with young people), and ensuring they are delivered in practice is one of the most pressing challenges in young people's mental health[36].

MQ's analysis of research funding[37] found that the majority of funding is awarded to studies evaluating existing treatments rather than looking at new interventions targeted at young people; this means that young people are often given interventions that have been mostly developed for and tested on adults.

Families

We know that our early years are greatly affected by the home environment and that factors in childhood affect our relationships, health and employment later in adulthood[38]. The adverse childhood experiences (or ACEs) study of over 17,000 adults has indicated that there is a strong graded relationship between the number of ACEs and the development of mental health problems. Such findings suggest that experiencing household dysfunction or multiple forms of abuse during childhood may pose harmful consequences for adult mental health.

Parenting programmes (such as Triple P and Headstart) are strongly evidenced interventions to support families. Applying a 'family systems' approach includes dynamics across the whole family and thus avoids overly focussing on mothers[39 40].

Schools and peer relationships

The school setting offers opportunities to help protect and support the mental health of young people. An evidence review commissioned for the recently published children and young people's green paper[41] identified some specific ways in which schools have an important role both in identifying mental health issues at an early stage, and in helping to put in place support for pupils experiencing problems. The review found that:

- The school environment is well suited to a graduated approach to children and young people's mental health, where those at risk can be identified and interventions can be offered to address problems.
- The school environment can present triggers for many difficulties (such as social anxiety).
- The school environment is non-stigmatising, making interventions offered in this context more acceptable to children and young people, and their parents[42].

Teaching young people about coping strategies and resilience in addition to building a supportive school environment can protect well-being and enhance learning[43]. Low level interventions that are provided in schools - for example, mindfulness - are showing promising results and have been found to improve attentiveness, self-esteem and concentration in school[44]. Peer relationships are important to young people's well-being and many programmes, including anti-stigma campaigns across the UK, focus on peer support as means to improve well-being and self-esteem.

Research in real-world settings

Research funding needs to be targeted specifically towards developing interventions for, and with, young people, evaluating those interventions and ensuring they are implemented in practice – a life course approach to research recognises that the perinatal period, childhood and adolescence are critical development periods where young people are at risk.

Research in real world settings can draw on a broad range of research methods such as action research, ethnography, programme evaluation and participatory research to address critical research questions or generate hypothesis for further investigation. Practical barriers often mean that research is not taking place in real world settings which can delay implementation and wider systematic roll out of innovations that are taking

MQ's commitment and recommendations

MQ Recommends: Research Funders and Commissioners identify and prioritise the development, testing and evidencing of new interventions and support for young people.

MQ Recommends: Research Funders and Commissioners should prioritise the evaluation of interventions and support in 'real world settings' where young people grow, live, study and work. Research in 'real world settings' can also address questions around social inequality.

Conclusions: A way forward for mental health research and **young people**

The Government's new ten-year Mental Health Research Framework, tells us how much we still must learn – and how much there is to do to fill in the major gaps in our knowledge.

It's true that, in many ways, these are unprecedented times for mental health. Governments from across the UK, all political parties and the Prime Minister have made mental health a priority. Last year, Theresa May recently called the devastation wrought by mental illness 'one of the burning injustices of our time'.

Yet the reality on the ground continues to reflect little of this change. We know that long waiting times and unequal access to young people's mental health services are putting lives at risk and emergency services are handling more mental health cases all the time. It's a sad reflection of where we are, that people are in crises before they get the support they need.

It's an exceptionally challenging time for our health services, but the issue runs far deeper than that, and to ignore the role that research can play in addressing this situation is to accept a status quo that is failing people.

Research brings with it the potential not only to develop more effective, more targeted responses, but to do so in ways that ease the burden on the health service. At a time when mental health conditions cost the UK £105bn each year, finding effective ways to intervene far earlier with young people could have profound consequences for individuals, communities, and for society.

Prioritising mental health research could help us to bridge the major gaps in our knowledge, gaining greater understanding and insights into mental health and helping us to prevent problems down the line. Research must be at the 'front and centre' of UK policy approaches to supporting young people if we are going to make progress in addressing the mental health crises of our time.

Our policy priorities

- **Research Funding:** we know that not enough is spent on research and to ignore this fact is to do a great injustice to 1 in 4 people affected by mental illness. **We want the Government and devolved nations across the UK to commit to a growth in mental health research that reflects the burden of mental illness.**
- Data is critical to understanding mental illness. **Informatics projects targeted at young people should be established and supported to expand the use and linkage of data. Access to currently available national datasets should be accelerated by streamlining legal and ethical approvals.**
- Young people offer unique insights into their own experiences. **Research funders and those carrying out research must incorporate a vision and commitment to meaningful involvement of young people in development, dissemination, delivery and governance of research.**
- We need more research taking place in 'real world settings': **Research Funders and Commissioners identify and prioritise the development, testing and evidencing of new interventions and support for young people. Priority should be given 'real world settings' and addressing social inequality.**

Appendix 1:

Snapshot: policy initiatives focussing on children and young people

England

The 2015 Taskforce co-chaired by NHS England and the Department of Health was influential in advancing children and young people's mental health and produced the strategy, *Future in Mind* (2015). *Future in Mind* identified some important actions for research including regular *'detailed prevalence surveys and reliable, routine (…) outcomes data'*[45]. In December 2017 the Department of Health and Department of Education published a Green Paper for Children and Young People's Mental Health – at the time of writing this was out for consultation.

Wales

Policy developments include the *Well-Being of Future Generations (Wales) Act 2015* which looks to improve the social, economic, environmental and cultural wellbeing of Wales and has mental well-being and 'future generations' at its heart. It commits public bodies to do this in a sustainable way to take account of people's lives in the future[46]. Key themes in the 10-year Mental Health Strategy in Wales, and the recent Delivery Plan 2016-2019 that accompanies it, include: children and young people, prevention and the role of evidence. There are commitments to improve data and use service user outcome measures in mental health research[47].

Scotland

Scotland's recently published 10-year mental health strategy 2017-2027 has prevention and early intervention as one of the key priorities. Ambitions for children and young people include that every child and young person has appropriate access to emotional and mental well-being support in school and evidence-based, parenting programmes should be available[48]. Scotland is also home to several important longitudinal and large cohort studies[49].

Northern Ireland

Mental illness is the largest cause of ill health and disability in Northern Ireland and there are higher levels of mental illness than any other region in the UK. It is estimated that around 45,000 children and young people in NI have a mental health problem at any one time and that more than 20% of young people are suffering 'significant mental health problems' by age 18[50]. Policy initiatives include recent cross-party vote to have a Mental Health Champion in Northern Ireland and a newly published health and well-being strategy[51].

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