# The Five Year Forward View Mental Health Taskforce:

public engagement findings

# CONTENTS

## Foreword

In March 2015 NHS England launched a Taskforce to develop a five-year strategy to improve mental health outcomes across the NHS, for people of all ages. Essentially, this will be a 'Mental Health Five Year Forward View' which clearly sets out how national bodies will work together between now and 2021 to help people have good mental health and make sure they can access evidence-based treatment rapidly when they need it. Collectively, we have a chance in a generation to deliver change that is achievable, urgent and necessary. This is an important opportunity to improve experiences and outcomes for people of all ages.

Our approach is one of co-production – involving people with lived experience of mental health problems, carers, professionals, providers, voluntary organisations and the component parts of the NHS – who are all part of the Taskforce. Our first step has been to find out what people want to see change, and this interim report reflects what they have shared and sets out what will happen next. Over the past few months we have been reviewing the rich existing evidence-base and recent strategies, and directly engaging with people with lived experience, organisations and professionals to establish their priorities for change. We are positively overwhelmed by the passion, enthusiasm and vibrancy of the movement of people ready and willing to transform mental health outcomes right across the NHS.

We're also painfully aware of just how many issues people have consistently raised that have not yet been meaningfully addressed through previous efforts. This is particularly true for those who have experienced or are experiencing major inequalities in access to care, in how people are treated and in outcomes - in part because of who they are, where they live or because of their mental health problems. We've heard countless descriptions of the nature of the problem and while we have found pockets of the country with aspects of high quality care in place, there is a long way to go before we are truly valuing people's mental and physical health equally.

The Taskforce is determined to set in motion a series of steps to transform the system so that, among other things, it commissions for outcomes and tackles unwarranted and unnecessary variations in care and support. Our strategy on priority areas for change is being co-produced in partnership with the arms-length bodies and implementation will be aligned across the national agencies who are members, including Care Quality Commission, Health Education England, NHS England, Public Health England, Monitor and Trust Development Authority. The strategy will include a year-on-year milestone map setting out exactly what each organisation is committed to achieving and by when, including how this will be monitored and reported on for increased transparency.

There are enormous opportunities for leaders across England to make urgent headway to radically improve outcomes in their own backyards and we're invigorated by the commitment and tenacity of many to find new solutions to tackle old problems. A strategy is not worth the paper it is written on unless it is put into practice. So while we will deliver a meaningful and credible strategy, it is only by working together that communities – made up of commissioners, providers, voluntary organisations and people with lived experience – can achieve the scale of change people are desperate to see.

Lastly, the evidence-base is clear that so much of what good mental health is about, individually and across society, depends on a wide range of socio-economic and environmental factors and it needs, therefore, concerted action from a very wide range of leaders across public life. While the NHS has a fundamental role, the NHS alone cannot transform mental health outcomes across England. So while what we are producing is for the NHS, the Taskforce has a shared goal to make mental health 'everybody's business'.

The Taskforce is deeply grateful for the significant volume of input from individuals and organisations. We'd like to thank all those who have contributed to the process to date – your views are crucial in shaping our work. When we publish the strategy in the autumn, bringing together the collective views of people with lived experience, carers and professionals, we will be signalling a new era for mental health care, demonstrating commitment through action across the system.
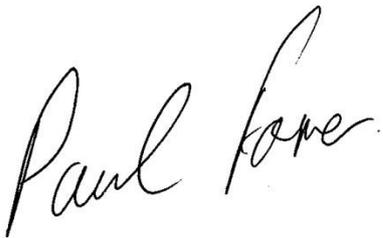
**Paul Farmer, Chair (Chief Executive, Mind)**

**Jacqui Dyer, Vice-Chair (Expert-by-Experience)**

## Introduction

1. Since April 2015, in addition to the expertise of the membership, input to the work of the Mental Health Taskforce has come via five routes:
   - An online survey and independent analysis of results;
   - Written submissions from organisations and individuals;
   - Formal meetings of the Taskforce;
   - Specific engagement events; and
   - Individual meetings and written input from a range of experts.

2. In total, to date the Taskforce has heard from:
   - 20,473 people who participated in an online survey developed by Mind and Rethink Mental Illness, which included people with lived experience, carers and health and social care professionals. 10,000 people provided complete and detailed information about their priorities for change. Broadly speaking, themes were consistent across respondents.
   - 250 people with lived experience and carers who participated in intensive engagement events hosted by Mind and Rethink Mental Illness, which explored people's priorities for change in detail. In particular, two events focussed on black, Asian and minority ethnic (BAME) communities and those easily excluded from such processes.
   - 60 individuals currently detained in secure mental health services, who were supported by service staff to send in written survey responses; and
   - 26 organisations that sent formal written submissions to the Taskforce via email.

3. The following summary represents the amalgamation of findings and content received by the Taskforce through engagement. Three clear themes have emerged – **prevention, access and quality**. The importance of integrating care and support was also identified as a critical factor to the successful delivery of equitable access and improved outcomes. The need to prioritise equality – particularly for BAME groups, older and younger people – also came out strongly across each of these themes.

4. Parity between physical and mental health is necessary but not sufficient; we must also tackle the huge variation in access to services between different groups of people. Given how underdeveloped the mental health system is and the chronic under-investment in services in past decades, a fourth cross-cutting theme will be the changes needed to infrastructure (data, payment, workforce, digital architecture etc.) that are required if we are to make meaningful improvements to services.

5. It should be noted that while the majority of respondents clearly articulated priority areas for change, outcomes and principles, a small amount of content was provided regarding specific actions that national bodies can undertake within their domain of control. It is the responsibility of the Taskforce to respond to what people have described as priority areas for change and to set out clear, measurable actions that the national arms-length bodies (ALBs) will work on together to deliver change.

6. The remit of the Taskforce is the NHS. Yet some changes people described which can contribute to prevention and improve experiences and outcomes, include action that can only be led by various other government departments and industry. To that end, and to fulfil our Terms of Reference, the final publication by the Taskforce will clearly identify these interdependencies and suggest further areas for exploration by other agencies.

## Theme One: Prevention and stigma

7. Prevention of mental health problems - and tackling stigma - features highly in the priorities of individuals and organisations.

8. From a sub-sample of approximately 2,500 of survey respondents, 25 per cent of people cited prevention in their top three priorities for change, and 19 per cent cited stigma. Issues relating to prevention were given fairly equal importance by people with lived experience of mental health problems, carers and health and social care professionals. Specific themes they raised include:
   - Support for new mothers and babies;
   - Mental health promotion within schools and employers;
   - Being able to self-manage mental health;
   - Ensuring good overall physical and mental health and wellbeing: and
   - Getting help early to stop mental health problems escalating.

9. Nine per cent of respondents also specifically cited prevention work through schools, and seven per cent cited employers as having a crucial role to play in preventing and supporting mental health problems.

10. Tackling stigma was more of a priority for people with lived experience of mental health problems and carers, than for professionals. Respondents wrote about the importance of challenging stigma in various settings and highlighted higher levels of stigma within particular communities, such as within BAME groups.

   *"Helping the stigma to decrease will allow ethnic minority communities to reach out for help when needed."*

11. Relational aspects, such as social interactions and the importance of positive relationships, were described as crucial aspects of good mental health for people of all ages. It was suggested that while it is particularly important to recognise loneliness and isolation in older people, these issues can affect people of any age.

    *"As I live in a rural area the isolation and lack of support or help from my GP is a great worry as my mental health worsens due to knowing I am without professional help."*

12. Some groups were identified as being at particular risk of developing mental health problems, such as carers of all ages, people facing additional stigma and discrimination including lesbian, gay, bisexual and transgender (LGBT) people, people living with disabilities and older people, as well as people of all ages who experience adverse life events such as trauma, abuse, bullying, long-term unemployment or bereavement. People with physical health problems, learning disabilities (LD), dementia and Autistic Spectrum Disorder (ASD) were also cited as being at particular risk, especially where delayed diagnosis could be an issue. Some also discussed those at particular risk of suicide, such as young and middle aged men. Participants emphasised the importance of needs being identified whenever opportunities arise to do so through contact with services and targeted, tailored support for these and other groups.

    *"My husband committed suicide 2 weeks after his 51st birthday. He wouldn't admit it to anyone not even himself. He was, as many were, brought up to be the bread winners and had to look after and protect and work hard to provide for his family. These barriers need smashing down to the older men and for it to be ok and it doesn't mean they are weak or worthless and that they are still loved no matter what they feel."*

13. It was thought that much could be gained from a 'community asset' approach, particularly in working with community and voluntary sector organisations, including faith-based organisations, to equip people with knowledge and skills to understand and manage their own mental health and that of those close to them. This was considered especially important within BAME communities, since there are considerable inequalities for these groups in accessing information, support and services.

14. Similarly, some people called for greater use of social prescribing, which links people with mental health problems into social activities in the community for wide-ranging benefits to overall health, including the opportunity to develop social networks.

*"We need social prescribing to improve intergenerational resilience and reduce loneliness and isolation."*

15. Many people discussed the importance of addressing the broader determinants of good mental health and mental health problems, such as good quality housing, debt, poverty, employment, education, access to green space and tough life experiences such as abuse, bullying and bereavement. Understanding the causes of mental ill health, including social and psychological factors, was considered a priority for research funding.

*"Recognition that much mental ill health arises from poverty, lack of social cohesion and feelings of lack of agency created by unequal society."*

16. People wanted mental health research to be equitably funded, and to have parity with other areas of health research.


## Theme Two: Access and choice

17. Timely access to effective, good quality evidence-based mental health treatment and therapies in response to need, always in the least restrictive setting, was a primary concern for the majority of survey respondents. Over half (52 per cent) of people said access is one of their top three priorities, and 33 per cent cite needing choice of treatment. 10 per cent specifically mentioned greater access to a range of psychological therapies in their top three priorities and wanted access and choice from a full range of evidence-based psychological therapies for all who need it irrespective of age, tailored to their specific needs, such as for children and young people, individuals living with severe mental illness, personality disorder etc.

*"My adult son has been sectioned 4 times. We see the pattern evolving over about a year. We inform the NHS team of the early warning signs. Patient confidentiality overrules duty of care so they do not tell us anything. He reaches crisis point and is admitted to hospital. After a month or two he recovers, but the pattern repeats. What a waste of NHS money in letting him reach crisis. The personal cost to him is higher, but that doesn't show on NHS accountants books."*

18. Of the formal submissions from organisations, around a third discussed the need for improved access to effective treatment generally, with around the same number specifically citing improved access for older people, improving crisis care and increasing the range of interventions for people to choose from. Other submissions raised the importance of targeted support for people who currently have the worst access and outcomes, such as some BAME communities, children and young people, older people, carers, LGBT people

and people living with multiple needs such as disability, long-term physical health conditions, Autistic Spectrum Disorder, substance use issues etc.

19. Aspects of access raised through the survey included substantially reduced waiting times and an expansion of the choice of services to include a broader range of therapies for different types of mental health conditions. Some people stated a preference for being able to self-refer for treatment.

20. Engagement event participants clearly expressed support for clear, evidence-based pathways into mental health services, with enforceable waiting times, as well as support while people are waiting to access them. People said that services should be compliant with guidelines established by the National Institute for Clinical Excellence (NICE), particularly around the use of medication, physical restraint and seclusion of individuals within inpatient and secure settings, and that care should be 'joined-up' around the person.

21. People described needing to be able to access help 24 hours a day, 7 days a week - especially for crisis or inpatient care. People said that if they were acutely unwell, there needed to be sufficient high-quality services available locally to enable them be treated close to home, so that individuals could remain rooted in their communities and near people within their support networks. There was also a desire expressed for greater consistency of availability and quality of services across the country.

*"If you feel unwell in the evening, during the night or at the weekends and bank holidays there is no choice but to go to A&E. There's no support out there during these times. It's crucial that this is changed for the benefit of service users, their families and carers."*

22. People described at length their experiences of care provided through GP practices and primary care services, which were often their first port of call if they were concerned about their mental health or the mental health of a loved one. Event participants in particular described a lack of a clear offer of support where they were not eligible for secondary care services.

23. People, especially young African Caribbean men, described what was currently provided as too heavily reliant on medication. Some people described negative experiences of approaching their GP for help, resulting in going to A&E. Participants also described the need for primary care to be more integrated with specialist mental health services and also called for wider sources of support and activity within their community.

24. Accessibility of services was raised and people wanted improvements to target those experiencing the poorest access, experience and outcomes, including BAME communities, LGBT people, children and young people, older people and people with multiple needs such as substance use, learning disability, dementia or long-term physical health problems.

*"My 12 year old daughter is currently struggling with acute mental health problems and has been begging for help. I have had to chase her referral through the NHS system and all the while, I am begging for affordable, accessible and efficient private NHS approved contacts to get a quicker diagnosis so I can help my daughter!"*

25. Groups of people currently excluded from any kind of treatment or care due to poor experiences of seeking support need to be provided with targeted support in primary and community services (including BAME groups, LGBT people, young people, older people and people with long-term conditions, learning disabilities and Autistic Spectrum Disorder).

*"Making physical and mental health care equally important means that someone with a disability or health problem won't just have that treated, they will also be offered advice and help to ensure their recovery is as smooth as possible, or in the case of physical illness a person cannot recover from, more should be done for their mental wellbeing as this is a huge part of learning to cope or manage a physical illness."*

26. There was a clear call for support and interventions to always be provided in the least restrictive setting appropriate to meet a person's needs, at any age. This was specifically cited by 15 per cent of survey respondents as a top priority. In engagement events, participants called for: provision of good quality home treatment; access to short stay crisis or recovery houses (where a person experiencing the onset of crisis can elect to stay in a respite setting providing intensive treatment and practical support); longer-term specialist residential services for those who need them (instead of long stays within secure inpatient services); and voluntary admission to inpatient care for those who need it, which is not always possible when thresholds for inpatient care are extremely high.

*"If they are ill for the first time it is vital the family can keep in close contact, so a close to home ward for acute mental health problems is necessary."*

27. People described the need to be provided with a clear reason for admission to inpatient mental health care, including secure settings, as well as a care plan and planning for discharge. People wanted to only be admitted to inpatient care if it was the most effective means of treatment. The majority of respondents currently detained in secure care services prioritised access to

crisis care as a key aspect of preventing admission into secure care services, where not strictly required.

28. People expressed a desire to tell their story to the health and social care system once, asking for professionals and services to join up to share relevant information about an individual's goals and care plans.

29. Survey respondents ranked different types of interventions in order of priority for improved access and quality. The top five areas people prioritised are:
    - Early intervention;
    - Psychological therapies;
    - Home treatment;
    - Information and skills to manage one's own mental health; and
    - Mental health awareness among the public.

## Theme Three: Quality and experience

30. People raised several aspects of the experience of being supported to respond to mental health problems. Of people citing choice as a top priority, 13 per cent described the importance of having the right information to make meaningful decisions about their treatment. Similarly, 13 per cent of people stated the need for wider diversity and skill mix in NHS staff, including the need for peer support and more staff with psychological support skills.

31. Some 12 per cent cited the importance of care planning, including co-production of care plans between professionals and individuals, involvement of carers and a holistic approach incorporating types of support and proper information sharing between services.

32. People expressed the need to have more control over their own care and to access the support that would work best for them as an individual, in line with the principle of 'no decision about me, without me'. People reflected the view that, too often, care was 'done to' them rather than shaped with them and that health professionals did not systematically listen to them or take their concerns seriously.

33. There was some emphasis on the importance of staff and services having clear protocols for working appropriately to involve carers. Carers described being blocked from information sharing or involvement - despite playing a potentially crucial support role - and the impact this has on them and their relationship.

*"There should be better support for families of those affected by serious mental health problems. The treatment I received during the worst part of my daughter's illness was appalling and unhelpful to my daughter. It added immensely to the trauma I was going through in adapting to my daughter's serious condition. It was like having someone beat you up when you are grieving a loss."*

34. People wanted to be provided with information about their rights, their condition and the services and support available to them, so that they could decide for themselves when they needed support and what that support should look like, in partnership with clinicians.

*"Genuine choice in terms of service received needs to be higher on the agenda, including alternatives to the medicalisation of distress."*

35. People raised particular issues around medication, where many reported that they were not always given full information about potential side-effects, or were put on medication before other support options had been explored. Where people wanted to reduce or come off medication, they described a need for more support to be available to help them do so. There were calls for more research into the long-term effects of psychiatric medication.

36. Within the survey, events and submissions, people described encountering stigmatising attitudes from some staff within mental health services, as well as staff in the wider NHS, including GP surgeries and non-clinical staff. Event participants said that they wanted to be treated as an equal, to be taken seriously and to be treated by staff who are positive about the future. They wanted professionals to have a better understanding of the psycho-social causes of mental health problems, as well as the symptoms, particularly for people with complex needs. They wanted professionals to treat 'the person, not the diagnosis'.

*"We need staff actually showing respect for patients with mental health problems and acknowledging that they are people who have a character and abilities beyond their mental illness - we are more than our problems."*

37. Professionals and professional bodies emphasised the importance of responding to the health and wellbeing needs of NHS and social care staff themselves, and the need to improve morale and the psycho-social working environment, especially given ever increasing pressures. There was an expressed view that it was critical to recognise that environment and working practices could have an impact on the wellbeing of the workforce.

*"Being both a junior doctor training in psychiatry, and a patient with mental health problems, enables me to experience both sides of the NHS, and I feel this gives me a great advantage and insight. Whilst a lot of the work I experience on both sides is very positive, I am frequently amazed by the heavy workloads of my colleagues and those treating me. And I know that for me, this can in fact contribute to deterioration in my own mental health."*

38. Exploring and responding to this was highlighted as an essential requirement of improving the experience of care in NHS settings, as there was likely to be a relationship between the environment professionals were working in, the health and wellbeing of staff and their ability to consistently support individuals with compassion. People wanted the NHS, as employers, to ensure that the people it employed were working in a supportive environment which valued and catered for their mental health and wellbeing needs.

39. People described wanting frontline staff across the NHS, including support staff, to have the confidence and skills to support people's mental health needs. This included wanting staff to have the skills to work collaboratively to identify goals and plan care and treatment, and to involve carers appropriately and meaningfully. Developing a paid peer support workforce (people with lived experience) had considerable support.

*"A recovery mindset and an emphasis on the value of lived experience and peer support are vital."*

40. People gave a strong message that within mental health settings, particularly within inpatient and secure care, all aspects of a person's life, including healthy relationships, education, employment etc. needed to be actively supported through collaborative care planning.

41. There was support for staff across the NHS to have training in accredited Mental Health First Aid, increased mental health awareness, suicide prevention, LGBT awareness and cultural competency, including working with people from BAME communities. People wanted the training to be led by people who have used mental health services.

42. There was support for greater regulation of non-NHS providers, particularly counsellors and psychotherapists, to protect people who use their services and ensure a high standard of care.

43. People described wanting a greater say in what services are available in their local area and how they are delivered, calling for services to promote wide-ranging and much more meaningful involvement with people who used services. People wanted to be paid for their time and expertise when helping to develop services, in recognition of the expertise they bring.

*"There should be even greater emphasis put on peoples 'experience' and how experts by experience can be seen and used as real assets to design and develop services."*

44. There was also support for much more research led by experts by experience, looking at what matters most to people in relationship to prevention and treatment.

45. Survey respondents ranked ten aspects of NHS service delivery in order of their perceived importance for bringing about change, listed in the survey (with the option to choose 'other'). The top five given related mostly to workforce, as follows:
    - NHS services being more joined up;
    - Attitudes of staff within mental health services;
    - Recruiting staff with range of skills (e.g. psychological support skills, peer support);
    - NHS staff training; and
    - Attitudes of staff working in non-mental health settings.

# Appendix A: Methodology and work to date

46. Terms of the Reference for the Mental Health Taskforce were published on 27 March 2015 and can be found at http://www.england.nhs.uk/ourwork/part-rel/mh-taskforce/. Membership comprises Board level representation from the Department of Health, the Arms' Length Bodies (ALBs) and strategic partners including professional bodies, civil society leaders and experts by experience. The Taskforce is responsible for creating the first-ever 'all ages' strategy for NHS-funded activity, with the primary objective of improving mental health outcomes across the NHS through the lens of the Five Year Forward View.

47. Each member of the Taskforce is responsible for consulting with its constituent membership, including the provision of evidence and formal positions, ensuring that the views and expertise of the people it represents are input into the thinking of the Taskforce.

48. The Taskforce is supported by a secretariat at NHS England comprised of staff seconded from Rethink Mental Illness, with gift-in-kind staff assistance from Mind and the Royal College of Psychiatrists.

## Call for evidence

49. A survey of open and closed-ended questions using Survey Monkey was distributed to organisations and individuals to collect both quantitative and qualitative data, from 20 April to 5 July 2015. All responses from closed, quantitative questions were analysed independently by Informed Thinking. However, due to the overwhelming volume of qualitative data, analysis focused on priorities for change. A sub-sample (12 per cent of the overall sample), using stratified random sampling, was created ensuring that extra weighting was given to under-represented respondent groups. The complete analysis is published separately as an appendix to this document.

50. In April, a 'toolkit' was disseminated, containing questions that followed the same lines of enquiry as the online survey. This provided a framework for individuals and organisations to submit written responses to england.mhtaskforce@nhs.net. Between 27 March and 30 July 2015 the inbox received 32 written submissions from individuals including people with lived experience of mental health problems and mental health professionals, and 26 organisational submissions.

51. Formal written submissions from organisations were received from:
Age UK
Alzheimer's Society
Bradford District Care NHS Foundation Trust
British Society of Clinical & Academic Hypnosis (BSCAH)

Carers Trust
Clinks
Gloucestershire Young Carers
Making Every Adult Matter (MEAM)
Maslaha
Mental Health Commissioners Network
Metropolitan Police
Mental Health Immigration Detention Working Group
MQ Insight
National Autistic Society
NHS Confederation's Mental Health Network
NHS Heywood, Middleton and Rochdale Clinical Commissioning Group
Plymouth University Clinical Psychology Service User Group
Priory
Psychological Therapies Unit Community Interest Company
Psychologists Against Austerity
Rethink Mental Illness
Richmond Borough Mind
St Mungo's Broadway
Stonewall
Tavistock Centre for Couple Relationships & Relate the Relationship People
Yorkshire & Humber Commissioning Support

52. Funded by the Mental Health Strategic Partnership and NHS England, Mind and Rethink Mental Illness hosted four intensive workshops for people with lived experience, including carers. This included two events specifically for people from BAME communities, due to low response rates to the survey from these groups.

**Taskforce meetings**

53. Since the launch of the Taskforce, the membership has had four meetings between April and July 2015, with a further two meetings scheduled.

54. Early on, methodology was agreed – namely, to set priority ambitions likely to significantly improve mental health outcomes, across all ages, over a five year period. A framework for joint working was set, including that each outcome would be supported by measurable objectives for change, further supported by annual milestones for the ALBs with co-production providing system partners with meaningful opportunities to coherently address systemic barriers. Discussion identified four areas that reform would need to address: timely access to evidence-based care; embedding mental health within physical health pathways; community-based alternatives to inpatient care; and pathways out of care.

55. The Taskforce then established consensus on priority outcomes and functions for ALB delivery, drawing on content received through the call for evidence and the expertise of the Taskforce. It was agreed that content would be organised into themes that responded to priority areas identified through engagement.

56. The next two meetings of the Taskforce will finalise specific actions, metrics for outcomes and activity mapped within a year-on-year roadmap describing how ALB commitments will be delivered.

## Additional meetings

57. The Chair and Vice-Chair of the Taskforce have had a series of meetings and/or conversations with stakeholders, including NHS Citizens, Cancer Taskforce, Care Quality Commission, Carers UK, College of Occupational Therapists, Department of Work and Pensions, Health Education England, Health Foundation, Home Office, Local Government Association, Mental Health Providers Forum, Metropolitan Police, Maternity Taskforce, Monitor, National Voices, NHS Confederation's Mental Health Network, NHS England, NHS Providers Mental Health Network, Pharmacy Voice, Public Health England, Skills Active, South Central Ambulance Services NHS Foundation Trust, Recovery and Outcomes Groups (run by Rethink Mental Illness and funded by NHS England) and the Trust Development Authority.

58. Omission of any organisation who formally or informally contributed is accidental and not intentional.

## New supporting economic analysis

59. Two complementary strands of new economic analysis were commissioned to help inform the work of the Taskforce. The first strand seeks to identify a baseline of mental-health related activity and spend for Her Majesty's Government (HMG) and non-HMG sources. The second strand focuses on a review of evidence to confirm the cost and outcomes for specific evidence-based interventions and wider benefits across the public sector. The output of both of these new pieces of work will further inform the development of the strategy.

60. A brief review of previous strategies and their implementation methodologies has been commissioned, to ensure that learning is applied and informs the work of the Taskforce.

## Communication

61. Interested individuals or organisations can obtain further information or provide additional evidence by emailing england.mhtaskforce@nhs.net.

**Appendix B: Independent analysis of survey results**



**A brief report on a survey about people's priorities for change**

**Authored by Chiara Samele, Ph.D and Norman Urquía, Ph.D**

**Analysis and report commissioned by Mind and Rethink Mental Illness for the Mental Health Taskforce**

**September 2015**

## Summary of key findings

1. A total of 20,473 responses to the survey were received, although there were many incomplete responses; around half or less for most questions.

2. Over half of the people responding to the survey had personal experience of mental health problems and around a tenth of respondents overall reported this to be a severe and enduring mental health problem. Just under half of the entire sample was a family member or close friend of someone with mental health problems and around a quarter were mental health practitioners.

3. For a sub-sample of 2,434 respondents, access to services came highest in the priorities listed for change, followed by choice of treatments and prevention. Integration, self-management, perinatal mental health and transitions were less prominent.

4. Access featured highly for the three main groups examined, but was particularly important for respondents with personal experience of mental health problems.

5. Parity of esteem came within the top ten most frequently cited priorities for change, and mostly by those with personal experience of mental health problems and a family member/close friend. Funding was a primary area for change for mental health practitioners.

6. More joined up NHS services was a key way in which many respondents felt the above changes could be brought about. Other highly ranked items focused on staff, either in terms of the attitudes of mental health professionals or training and recruiting staff with particular skills.

7. For improving types of mental health support respondents overwhelmingly ranked early support/intervention as the most important.

### Limitations of the data

8. Difficulties of coding the large volume of qualitative data from the survey necessitated the use of a sub-sample of respondents; low response rates were received from Black, Asian and Ethnic Minority (BAME) and Lesbian, Gay, Bisexual and Transgender (LGBT) groups; and less than half the sample responded to questions, such as age and gender and other key questions.

### Introduction and survey aim

9. The Mental Health Taskforce was convened in March 2015, to develop a five year national strategy for mental health, covering all age groups. In order to ensure the forthcoming strategy is well informed, Mind and Rethink Mental

Illness carried out an online survey to gather the wide range of views of people with personal experience and professional expertise in mental health to input into the work of the Taskforce. This report outlines the key findings of the survey and the priorities for change indicated by respondents.

**Method**

10. A survey of open- and closed-ended questions was compiled and distributed to key organisations and individuals using Survey Monkey to collect both quantitative and qualitative data.

11. The questions in the survey included:
    - Peoples' experiences of mental health challenges (e.g. personal experience, carer etc.) (Qu.1);
    - Desired changes to mental health by 2020 (Qu.2);
    - what these changes mean for specific groups (e.g. children/young and/or older people) (Qu.4);
    - Examples of what is working in terms of mental health support (Qu.s 9-11);
    - Ranked responses to how different aspects of the NHS play a role in bringing about changes (e.g. NHS staff training, personal budgets, etc.) (Qu.7);
    - Order of priority for improving mental health support (e.g. alternatives to inpatient care, preventing mental health problems, etc.) (Qu.12); and
    - Respondents' demographic profile (Qu. s 15-22).

12. The data collection period was between 20th April to 5th July 2015.

13. All responses gathered through the closed-ended/ quantitative questions were analysed and are presented in this report. However, due to the over overwhelming volume of qualitative data gathered through the survey, this analysis focused on Qu.2 (priorities for change in mental health by 2020). A sub-sample of 2434 respondents (12% of the overall sample), using stratified random sampling was created. This ensured that extra weighting was given to under-represented respondent groups. The responses to Qu.2 from this sub-sample were coded and quantified into 27 categories. Details of these codes and their descriptors can be found in the Appendices.

14. The final sub-sample comprised the majority of Black and Asian Minority Ethnic respondents (1,028), Transsexuals (91) and Lesbian, Gay, and Bisexual & Transgender respondents (167), as well as other groups.

## Data analyses

15. Frequencies, percentages and descriptive statistics (e.g. mean averages for ranked responses) were calculated for all quantitative data derived from questions: 1, 7, 12, 15-22 using SPSS (version 20). Cross tabulations were generated to examine priorities for change in mental health (Qu.2) by group (e.g. people with personal experience, carers/close friend and practitioners). Each respondent gave three answers to this question, and these were combined into one large, multi-answer data set.

16. Software for analysing text responses, NVIVO (version 9) was used to explore some of the qualitative responses and to elaborate on the headlines given by the coded data from Qu.2 (e.g. to explain what 'access' means).

## Survey responses

17. A total of 20,473 responses to the survey were received, although there were many incomplete responses. For example, around half of the total number of respondents answered Qu.7 on how the NHS could bring about the desired changes and for Qu.12 around 8,000 respondents (less than half) submitted an answer to what order of priority for improvement they would like to see for mental health support.

## Demographic profile of *all* respondents

18. 41% of the entire sample responded to the question on age. Figure 1 shows the age distribution of these respondents.
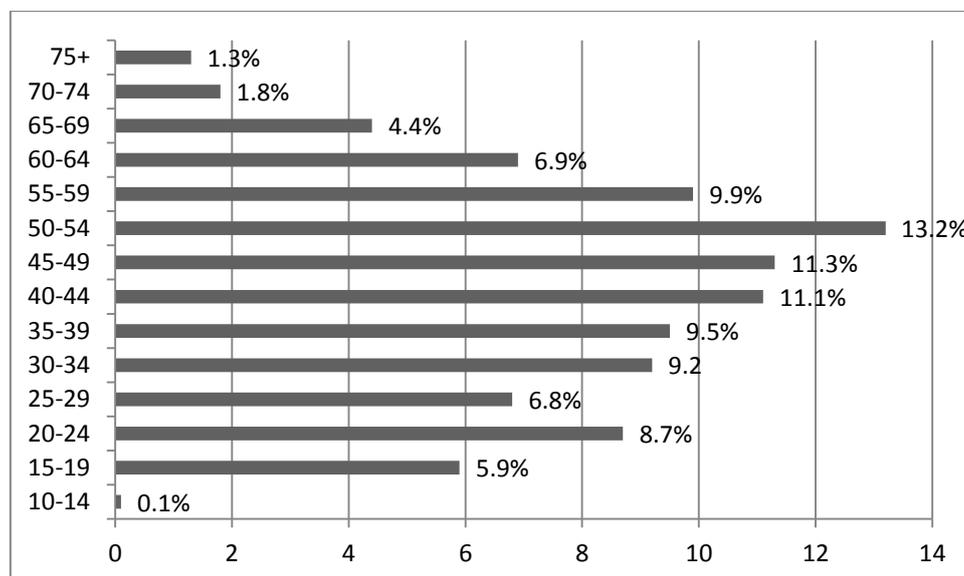


Figure 1: Percentage of respondents according to age groups (n=8380)

**Gender (6068 respondents)**

19. 72% (6,068) were women, 24.3% (2,044) and were men. 1.4% (121) identify as a different gender than that assigned at birth.

**Sexual orientation (8185 respondents)**

20. The majority of people were heterosexual (76.3%) and far fewer were gay men (2%), gay women (2.4%) or bisexual (7.1%).

**Ethnicity (8177 respondents)**

21. Most respondents were White British (81.3%). 2% were from Black and Asian Minority Ethnic groups (BAME). 6% were 'Other' and 2.9% were White Irish.

**Geographical spread of respondents (8404 respondents)**

22. 8,404 respondents noted the local authority area they currently reside in. There was a broadly even spread of respondents across most regions in England, except for London and Manchester which had a comparatively higher number of respondents (13.3% and 4.1% respectively) (see Figure 18 below).

**Experience of mental health problems and reported disabilities[1]**

23. 62% (12,697) of all respondents reported having personal experience of mental health problems and 4% with no experience of this. 10% (2,131) reported having a severe and enduring mental illness.

24. 48% (10,006) of the entire sample reported being a family member or close friend of someone with mental health problems.

25. For other disabilities, 2.3% reported having a sensory disability, 2.7% a learning disability and 5.1% a physical disability.

**Practitioners**

26. Around a quarter of all respondents were mental health practitioners (25.6%), 4.5% NHS practitioners (non-mental health) and the same proportion of social care professionals (4.3%).[2]

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[1] Respondents could tick more than one category; so could be both a family member or close friend but also have personal experience of mental health issues. The number of respondents for this section therefore exceeded 20,473.

[2] All practitioners (health, non-health and social care professionals) were merged into one group when examining priorities for change by group.

## How would you like things to be different in mental health by 2020? Changes to mental health and wellbeing (Qu.2)

27. Based on the sub-sample of 2434 respondents described above; the top five areas for change are:

- access to services (52%)
- choice of treatments (33%)
- prevention (25%)
- funding (21%)
- stigma and discrimination (19%)

28. The following figure illustrates the percentages of respondents reporting the areas of change they would like to see.
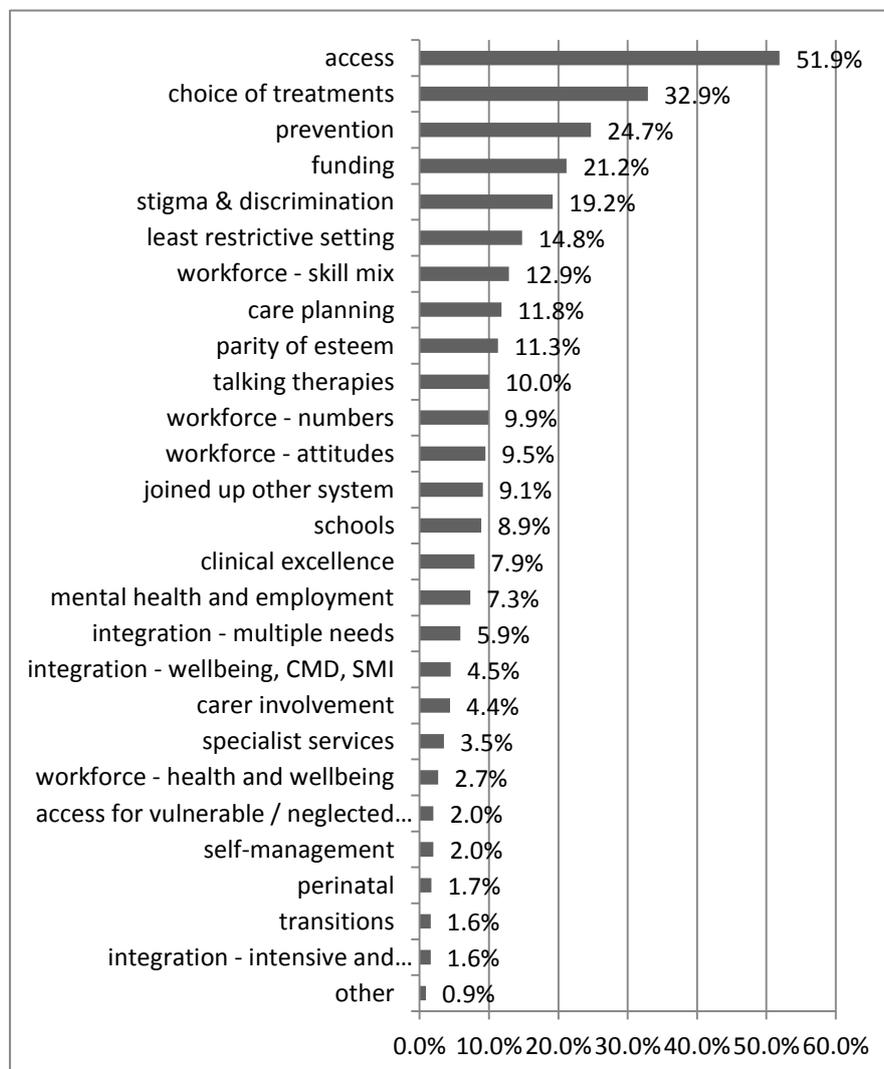


| | |
|---|---|
| access | 51.9% |
| choice of treatments | 32.9% |
| prevention | 24.7% |
| funding | 21.2% |
| stigma & discrimination | 19.2% |
| least restrictive setting | 14.8% |
| workforce - skill mix | 12.9% |
| care planning | 11.8% |
| parity of esteem | 11.3% |
| talking therapies | 10.0% |
| workforce - numbers | 9.9% |
| workforce - attitudes | 9.5% |
| joined up other system | 9.1% |
| schools | 8.9% |
| clinical excellence | 7.9% |
| mental health and employment | 7.3% |
| integration - multiple needs | 5.9% |
| integration - wellbeing, CMD, SMI | 4.5% |
| carer involvement | 4.4% |
| specialist services | 3.5% |
| workforce - health and wellbeing | 2.7% |
| access for vulnerable / neglected... | 2.0% |
| self-management | 2.0% |
| perinatal | 1.7% |
| transitions | 1.6% |
| integration - intensive and... | 1.6% |
| other | 0.9% |

Figure 2: Overall percentage of respondents identifying priorities for change to mental health by 2020 (Qu.2) (n=2434)

**Quicker access to mental health services**

29. Figure 3 details the types of responses concerning quicker access to mental health services/treatment generally, for example, easier access, shorter waiting lists and times, and access for all. For some, this meant '*less waiting between diagnosis and treatment*', and changes to the threshold for treatment so that '*you don't have to be about to kill yourself or someone else to qualify as needing help*'; and '*better access to treatment across the board whether talking therapy or crisis inpatient care*'.

30. For talking therapies, for example, respondents noted a wish for quicker and timelier access to these and reduced waiting times. This also included affordable access or not having to pay for private therapy or counselling.

Figure 3: Access to mental health services

**Better choice of treatments**

31. Choice of treatments was the second most common change requested. This included more use of technology in which to communicate with service users, for example using smart phones, email and the internet (Figure 4). Treatment choices that extended beyond simply offering Cognitive Behaviour Therapy (CBT) and/or medication was also specified by respondents, as well as having more information about what treatment options were available rather than being told what treatment would be given.
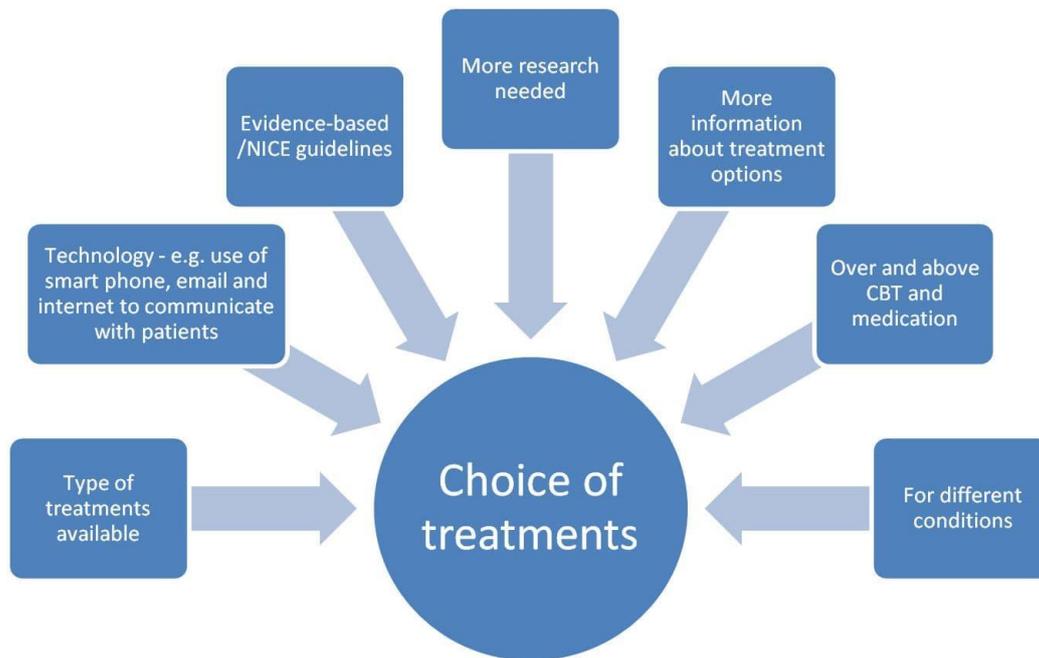
Figure 4: Choice of treatments

**More prevention**

32. Prevention was the third most popular area for change and appeared to focus on primary prevention, emphasising early intervention and wellbeing for children and young people (Figure 5). Secondary prevention to avoid further relapse and deterioration of a person's condition was also highlighted.
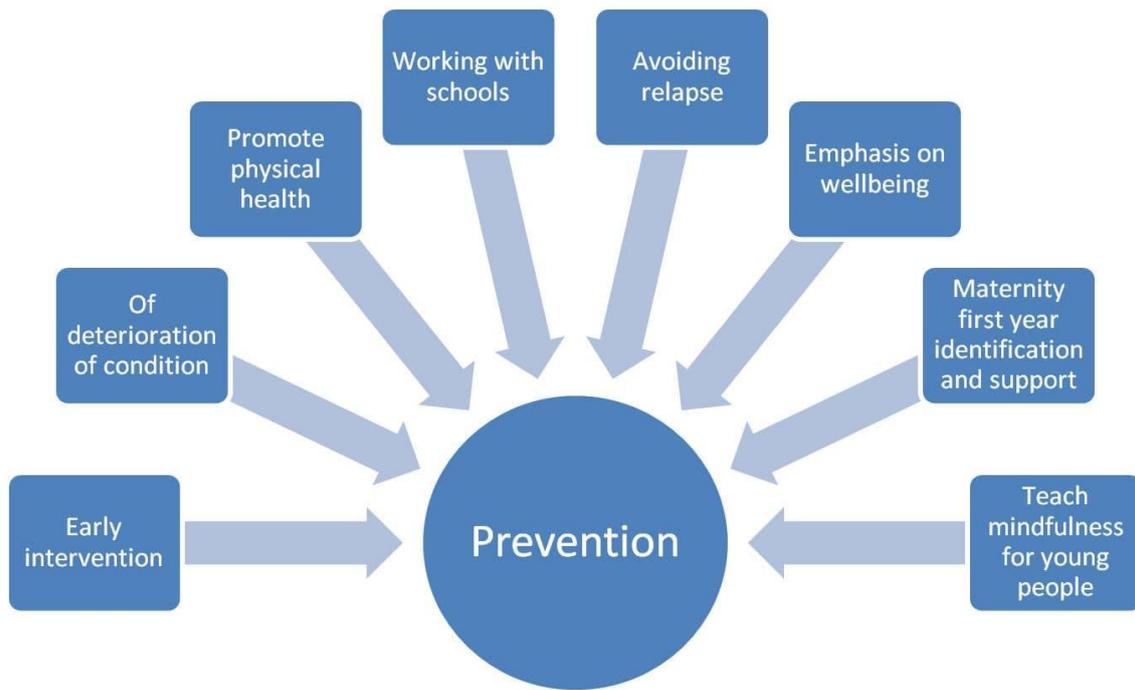


Figure 5: Prevention

**Increased funding**

33. This fourth area of recommended change included a multitude of items for additional funding such as prevention and parity with physical health (Figure 6). Improving commissioning, increasing efficiency and measuring value were also emphasised.



Figure 6: Funding

**Tackle stigma and discrimination**

34. There remains further work to be done in challenging stigma and discrimination, particularly for example certain groups such as men, LGBT and older people (Figure 7).  Placing mental health on a par with physical is again featured within this recommended priority for change.



Figure 7: Stigma and discrimination

**Least restrictive setting**

35. The need for better crisis care both in the community and in hospital was the sixth most popular area for change. Improved access to crisis services came with a suggestion of developing a '999' equivalent for mental health, having more alternatives to hospital and non-health based places of safety (Figure 8).
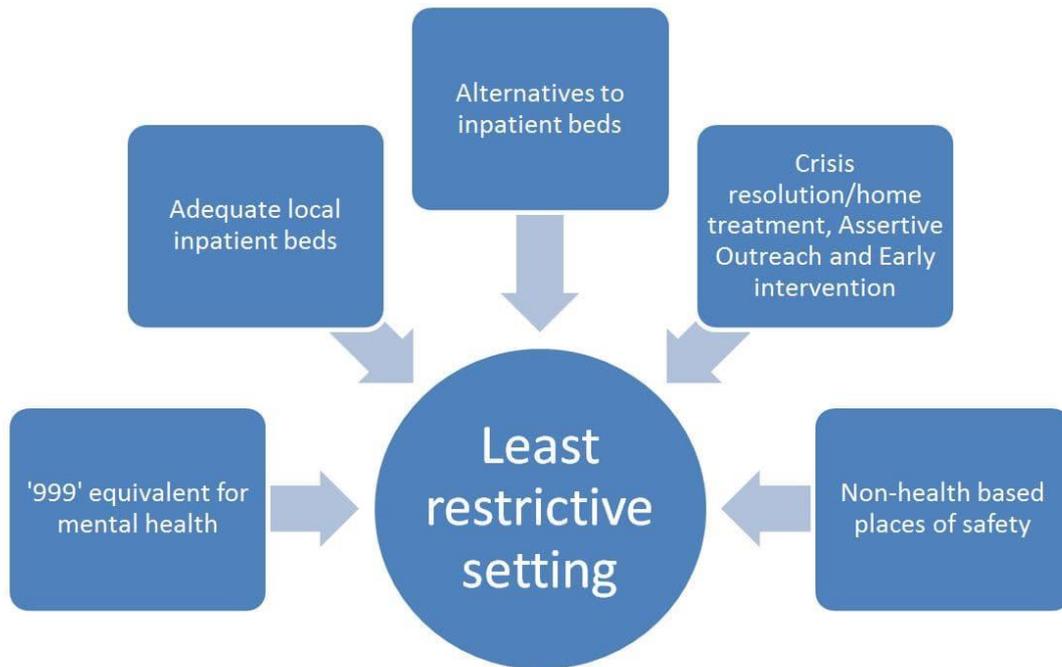


Figure 8: Least restrictive setting

**Improved workforce – skill mix and staffing**

36. Increasing skill mix and levels of staffing to ensure better coverage of community mental health services and continuity of treatment were examples of the type of change recommended for improving the workforce (Figure 9). The inclusion of peer support workers and better training for GPs in relation to mental health was also underlined.



Figure 9: Workforce – skill mix and staffing

**Improved care planning**

37. Care planning also included themes for better coordinated and continuity of care, incorporating other services into mental health and better follow-up care (Figure 10). Involving carers in care planning was also highlighted.



Figure 10: Care planning

**Better parity of esteem**

38. Parity not only concerned bridging the gap between physical and mental illness, but also for achieving parity for CAMHS, people with long-term conditions and ensuring parity in resourcing mental health services (Figure 11).
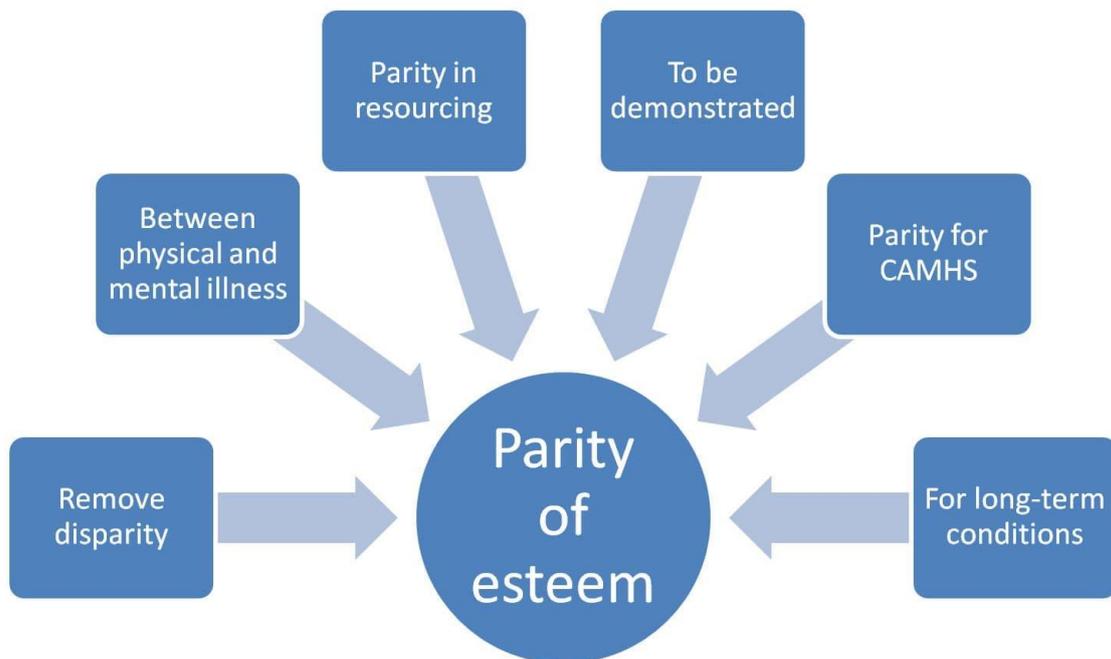


Figure 11: Parity of esteem

**More talking therapies**

39. Apart from requesting a wider range of talking therapies better access to these and more sessions were also desired (Figure 12).
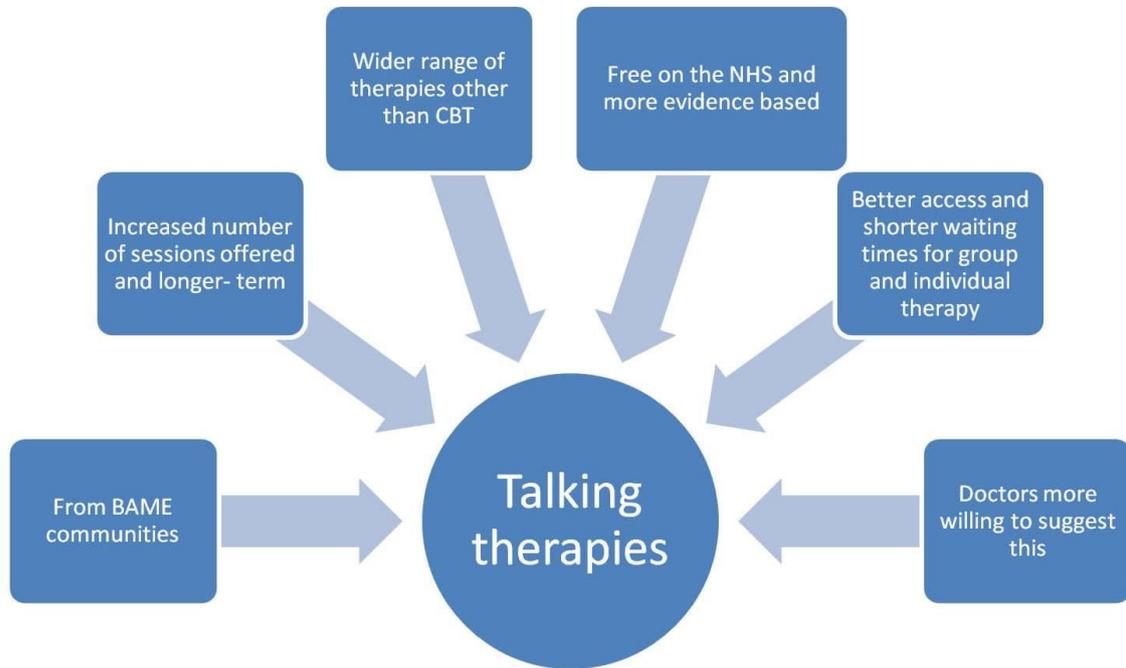


Figure 12: Talking therapies

**What was prioritised by different groups?**

40. The responses to Qu.2 were analysed according to three main groups – respondents with personal experience of mental health problems, family or close friend and mental health/health and/or social care practitioner. Figure 13 compares the percentages of the top thirteen desired changes by 2020 for these groups.

41. Access was the most common issue for all three groups, particularly for respondents with personal experience. Choice of treatments, prevention, workforce (skill mix) and care planning show similar percentages between all three groups. Funding and workforce numbers were notable areas for change by 2020 for health and social care practitioners.
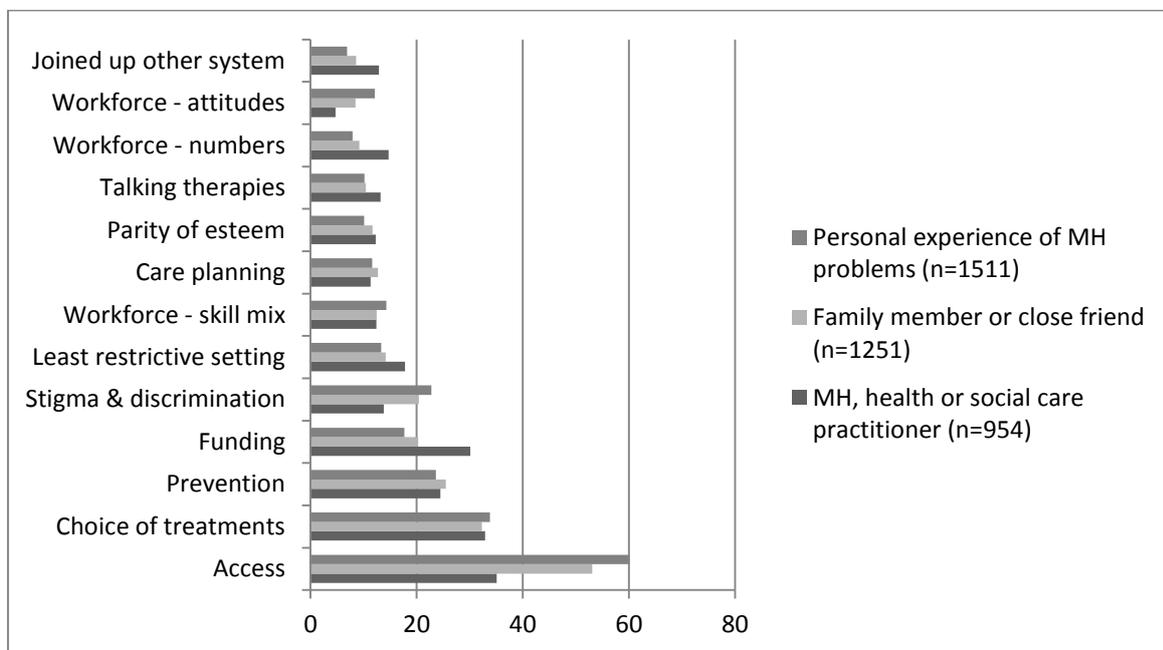


Figure 13: Percentage of respondents identifying priorities for change by group

## How much do different aspects of the NHS play a role in bringing about the changes you have described? Ranked changes in order of importance (Qu.7 - full sample)

42. Respondents were asked the extent to which different aspects of the NHS can bring about the above changes. Ten different items were listed and respondents were asked to rank these in order of importance where 1 was (most important) and 10 (least important). Around half of all respondents (n=10,200) answered this question. Figure 14 shows the mean ranks for each item.
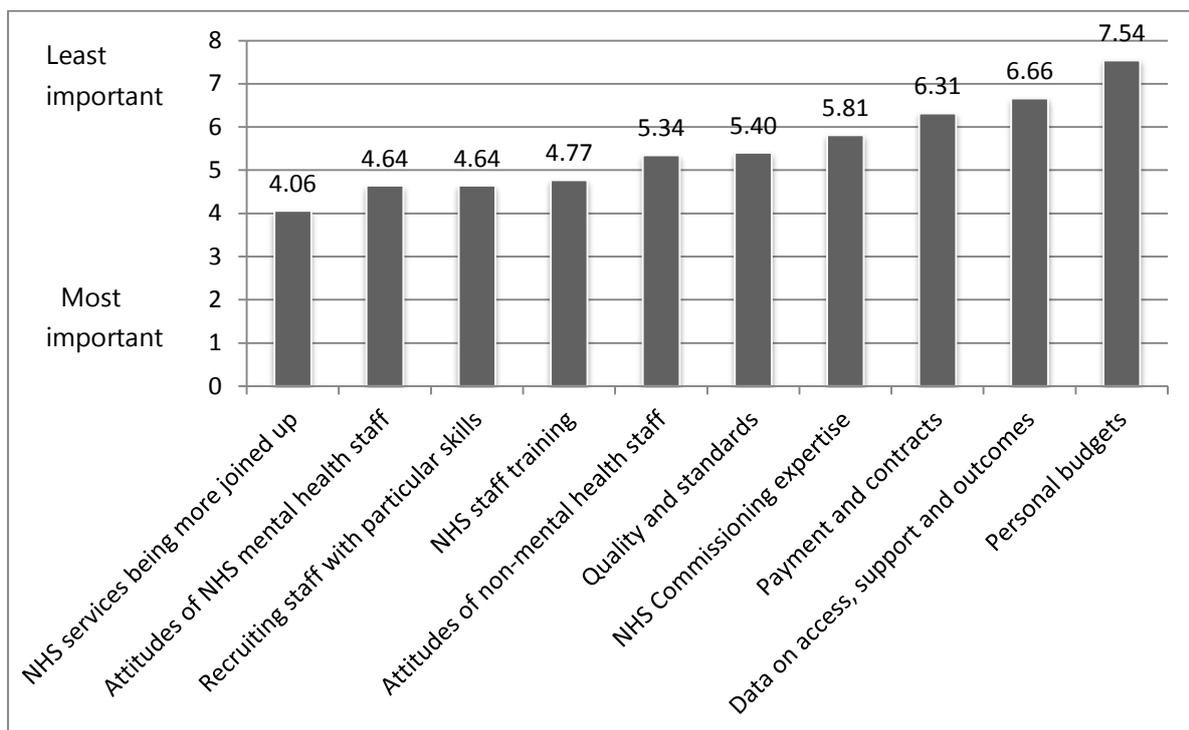


Figure 14: (Qu.7) Mean ranks for different aspects of the NHS to bring about change (n=10,200 approx.)

43. The most important items concerned:

- NHS services being more joined up, regardless of what part of the NHS a person was in contact with;

- Attitudes of NHS mental health staff;

- Recruiting staff with specific skills, such as those with lived experience or able to provide psychological therapy.

44. Personal budgets for people to spend as they preferred was ranked the least important.

45. When broken down by group, roughly similar percentages were found for most of the items listed in question Qu.7 (Figure 15). Slightly more family members and close friends ranked more joined up NHS services as the most important for bringing about change in mental health support by 2020.

46. Marginally more respondents with personal experience ranked attitudes of mental health/health staff as highly important, as well as recruiting staff with particular skills. NHS commissioning expertise and payment and contracts were ranked as most important by practitioners when compared to respondents with personal experience and family/close friends.
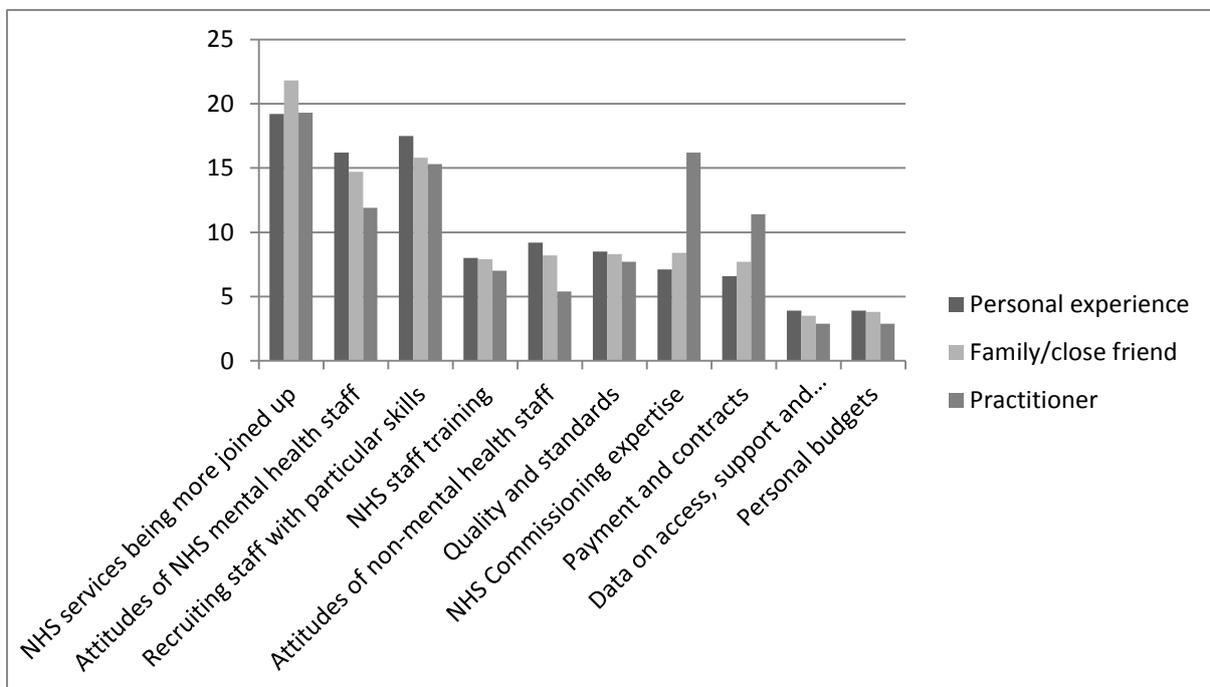


Figure 15: Percentage of respondents by group ranking items for Qu.7 as 'most important'

## What order of priority for improvement would you give the following types of mental health support? (Qu.12 - full sample)

47. Respondents were asked to rank fourteen areas for improving mental health support from 1 (most important) to 14 (least important). Figure 16 shows respondents' order of priority for improving the types of mental health support (mean ranks). Priorities receiving the 'most important' rating were early support/intervention for severe mental health problems, access to talking/psychological therapies and effective home treatment in a crisis.

48. Priorities ranked of lesser importance (with a mean rank higher than 9) were advocacy, support for specialist employment and personal budgets.
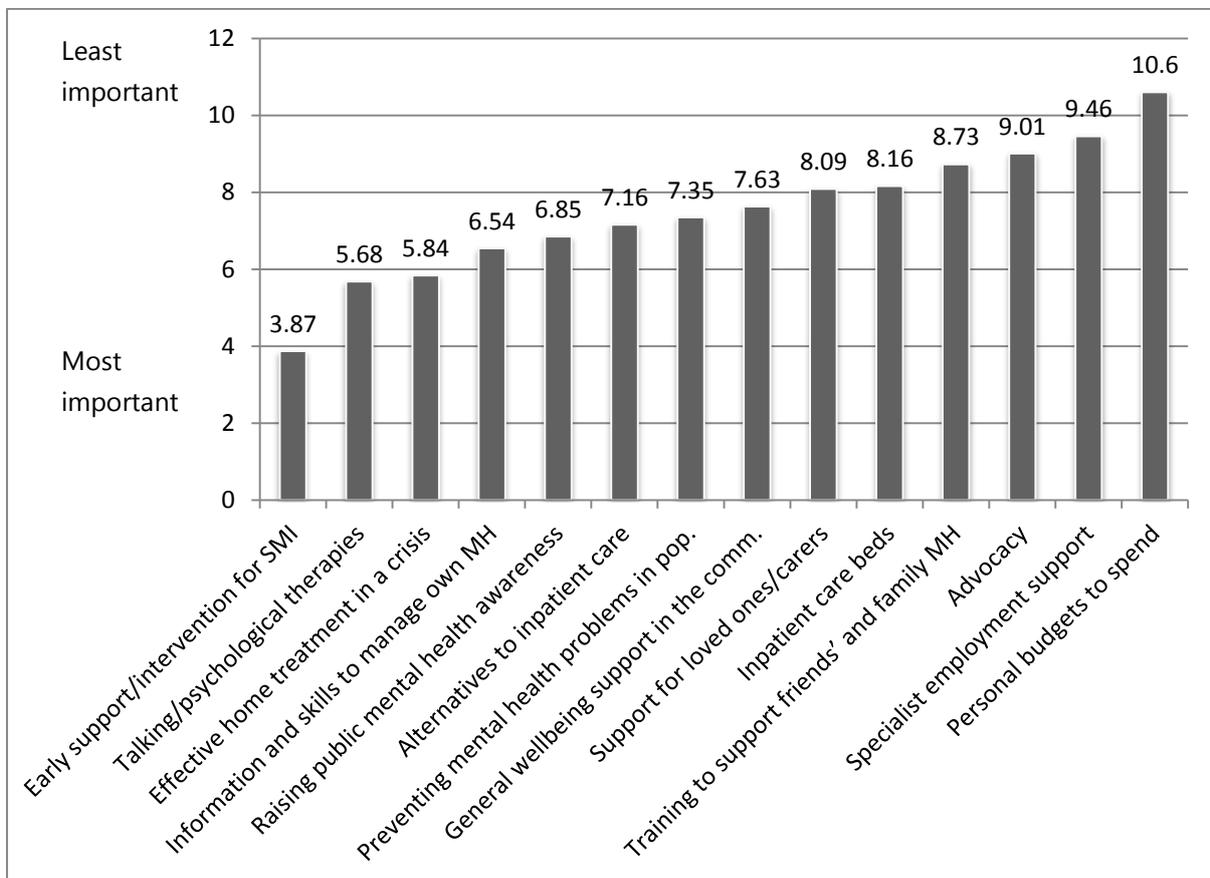


Figure 16: (Qu.12) Mean ranks for improving mental health support (n=8160)

49. Figure 17 shows the percentage of respondents ranking items from Qu.12 as 'most important'. All three of the main groups broadly rank these items from Q.12 in a similar way.

50. The exception to this was early intervention which was ranked most important largely by people with personal experience of mental health problems and family/close friend. Practitioners ranked talking therapies and preventing mental health issues in the population more highly.
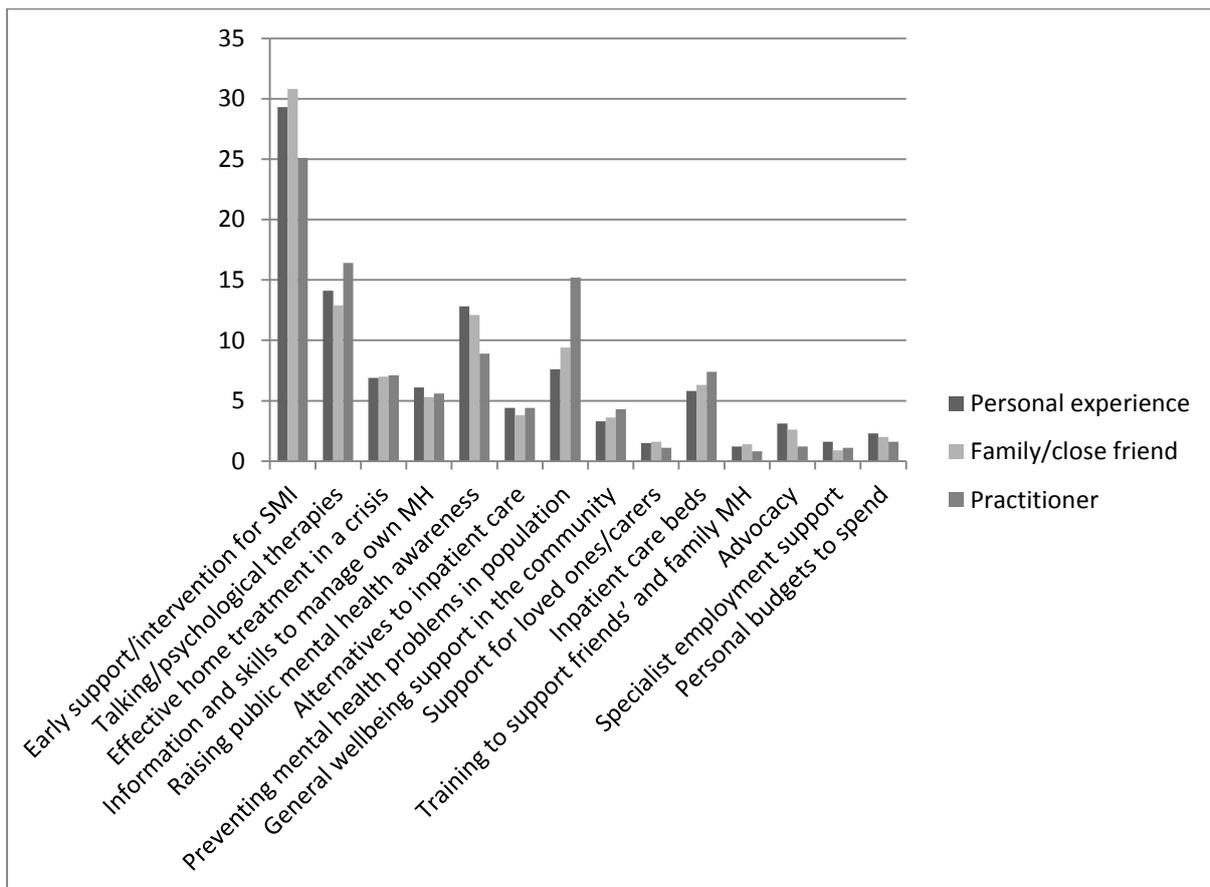


Figure 17: Percentage of respondents by group ranking items for Qu.12 as 'most important'

## Discussion of key findings

51. Most people responding to the survey had personal experience of mental health problems and around a tenth of respondents overall reported this to be a severe and enduring mental health problem. A large proportion of the entire sample was a family member or close friend of someone with mental health problems and around a quarter were mental health practitioners.

52. For the sub-sample of respondents, access to services came highest in the areas listed for change in mental health, followed by choice of treatments and prevention. Areas for change such as integration, self-management, perinatal mental health, advocacy and transitions were less prominent.

53. Quicker access featured highly for most groups, particularly respondents with personal experience of mental health problems and a family member/close friend. When qualitative responses were explored more closely, better access meant reduced waiting times and more timely access to support, particularly talking therapies.

54. Choice of treatments highlighted the need for more information about available treatments and using technology to communicate with service users.

55. Prevention of mental health problems was clearly emphasised, particularly prevention initiatives for children and young people. Early intervention for other groups such as new mothers, and reducing the risk of people with existing mental health conditions deteriorating or relapsing was also noted by respondents.

    *"We need better support for new mothers with postpartum depression. The physical aspect of pregnancy is well known but the mental affects are not."*

56. Parity of esteem was not among the most frequently cited priorities for change. Funding was a primary area for change for mental health practitioners.

57. More joined up NHS services was a key way in which many respondents, especially family members/close friends, felt the above changes could be brought about (Qu.7). Other highly ranked items focused on staff, either in terms of the attitudes of mental health professionals or training and recruiting staff with particular skills.

58. For improving types of mental health support respondents overwhelmingly ranked early support/intervention as the most important.

**Limitations of the data**

59. Despite a seemingly large number of respondents, in excess of 20,000 people, less than half of this sample responded completely to the various questions, including those concerning respondents' demographic profiles, such as age and gender and other key questions. Caution must therefore be exercised when interpreting the findings of the survey in view of the limited responses for many key survey questions.

60. Many of the survey questions were not quantified initially. The reason for this was to allow respondents to share their views using open text responses. This, however, generated an overwhelming amount of qualitative text which was difficult to code and quantify in the time available for analysing and writing up the survey. This report therefore provided the findings for a relatively small sub-sample of respondents with regards to Qu.2.

61. The survey attracted fewer numbers of respondents from Black, Asian and Ethnic Minority and LGBT groups despite attempts to increase this. However, the majority of respondents from these groups were included in the sub-sample for analysis and are reported here.

## Conclusions

62. This survey aimed to collect the views of a range of key stakeholders to underpin the development of the five year national strategy for mental health for all age groups. People with experience of mental health problems, families/close friends and practitioners working in mental health, social care and non-mental health services contributed to the survey.

63. The key findings point to the overwhelming importance of improving access to mental health care by reducing waiting times and enabling easier access through self-referral where necessary. Better and more timely access to talking therapy was considered key. Choice of treatments and prevention of mental health problems and further relapse/deterioration of an existing condition were also considered important to prioritise for change in mental health.

64. There remains further work to be carried out in continuing action against stigma and discrimination for certain groups and in a variety of setting, such as schools, the workplace and in the NHS.

65. Ensuring the workforce is adequately skilled, provides continuity of treatment and includes peer support workers are other priorities for improvement and change.

# Appendices

## Glossary of abbreviations

BAME – Black and Asian Minority Ethnic groups

CAMHS – Child and adolescent mental health services

CBT – Cognitive behavioural therapy

CMHP – Common mental health problems

MH – Mental health

SMI – Serious mental illness

## Table 1: Areas for change codes and their descriptors (Qu.2)

| Access | <ul><li>Waiting times (the time it takes to access a service is too long)</li><li>Ease of access (it is difficult to be referred to the service you would like)</li><li>Navigation (it is difficult to navigate the mental health system)</li><li>Self-referral (I want the ability to self-refer to services)</li><li>Thresholds (the severity of need required to access mental health services is too high)</li><li>Local (want to access services locally)</li></ul> |
|---|---|
| Access for vulnerable/ neglected groups | Men, Black, Asian, Minority Ethnic groups, LGBT, travelling communities (need specialist engagement/ encouragement to seek help from any health professional) |
| Care planning | <ul><li>Co-production (service users want to be involved in the planning of their care)</li><li>Follow up (need follow up care after being discharge from a service)</li><li>Consistency (want healthcare professionals to be involved in their care consistently (fewer changes and less staff turnover)</li><li>Continuity of care (there are fewer breaks or changes in care plan as people move between services)</li></ul> |
| Carer/ family involvement | <ul><li>Health professionals to involve carer/ family in the decisions about their loved one (with their consent)</li><li>Support for family/ carers (need to recognise the stress carers may feel and provide support (either formal or</li></ul> |

| | |
|---|---|
| | informal) |
| Choice of treatments | • Type of treatments available (want greater choice in the types of treatments available)<br>• Technology (using technology as a mode to deliver treatment choices)<br>• Evidence based (treatments must be evidence based<br>• NICE (NICE approved)<br>• Research (into new treatment options) |
| Clinical excellence | • Improvement in quality of services (there needs to be an improvement in the quality of services)<br>• Risk averse culture (NHS staff, managers are risk averse)<br>• Bureaucracy (there is too much bureaucracy interfering with NHS staff ability to provide care and support)<br>• Service user involved in shaping services (services must be shaped by the views of service users) |
| Funding | • Increased funding (mental health services need to be properly funded)<br>• Commissioning (commissioning of mental health services need to change)<br>• Efficiency (mental health services need to more efficient)<br>• Competition (need more or less competition, private provider competition)<br>• Measuring value (need to get better at measuring value)<br>• Cost of prescriptions (reduce or abolish cost of prescriptions) |
| Integration - intensive + on-going needs | • Joined up integrated care for people with intensive and on-going needs (medically unexplained symptoms, personality disorders, on-going vulnerability, etc)<br>• Liaison mental health (provide liaison mental health in Acute Trusts, including A+E departments) |
| Integration - multiple needs | Joined up integrated care for people with multiple needs (dementia, substance use, long terms conditions/ chronic physical health conditions, intellectual disability) |
| Integration - wellbeing, CMHP, SMI | Joined up integrated care for people with mental health needs (wellbeing, common mental health problems, serious mental illness) across mental health services (community services, primary care, secondary care, tertiary care) |
| Joined up other system | • Mental health services are joined up across other public services (social care, welfare, housing, voluntary sector police)<br>• Policy in other government departments (Department for Education, Ministry of Justice, Home Office, etc.) should not undermine/ obstruct progress being made in mental health policy |
| Least restrictive setting | • Inpatient beds (acute beds, child and adolescent, adult, older adults)<br>• Community mental health teams (Crisis Resolution/ |

| | |
|---|---|
| | <ul><li>Home Treatment teams, Assertive Outreach teams, Community Mental Health Teams, Early Intervention in Psychosis teams)</li><li>Alternatives to inpatient admissions (crisis houses etc)</li><li>Non-health based places of safety (not to use police cells)</li></ul> |
| Mental health and work | <ul><li>Support into work (support to help those with mental health problems find and retain meaningful employment)</li><li>Welfare issues (support in accessing benefits, fair benefits - sanctions)</li><li>Sick pay (for those on leave from work because of a mental health problem)</li></ul> |
| Other | Does not fit into themes, cannot understand comment |
| Parity of esteem | <ul><li>Parity of esteem compared to physical health (mental health to be considered equal to physical health)</li><li>Variation across the country (variation in the services provided, quality or outcomes depending on where you live)</li><li>Political interest (support from ministers and other politicians for mental health)</li></ul> |
| Perinatal | Treatment and support for women and new mothers with known or emerging mental health problems (antenatal period, perinatal period, post-natal period, parenting support) |
| Prevention | <ul><li>Prevention of poor mental health (early intervention, prevent deterioration in mental health condition)</li><li>Prevention of poor physical health (promoting good physical health, early intervention)</li></ul> |
| Schools | <ul><li>Identification, treatment and support for children adolescents and young adults in schools (mental health on school curriculum, mental health support in primary and secondary schools</li><li>Mental health treatment and support available at universities)</li></ul> |
| Self-management | <ul><li>Awareness of mental health issues, signs and symptoms</li><li>Knowledge of where to find tools and learn the skills needed to look after own mental health</li></ul> |
| Specialist services | Gender clinics, eating disorder services, therapeutic communities |
| Stigma & discrimination | <ul><li>Public attitudes (perceptions of people with mental health problems)</li><li>Media reporting (more sensitive media reporting)</li></ul> |
| Talking therapies | <ul><li>Access (easier access to talking therapies )</li><li>Number of sessions offered (greater number of sessions offered)</li><li>Expanding the range of therapies offered (therapies other than cognitive behavioural therapy)</li></ul> |
| Transitions | <ul><li>Child and Adolescent Mental Health Services to Adult</li></ul> |

| | |
|---|---|
| | Mental Health Services<br>• Adult Mental Health Services to Mental Health Services for Older People,<br>• Better transitions at the interface between inpatient and community mental health services |
| Workforce - attitudes | • Culture (NHS culture affecting staff ability to provide compassionate care)<br>• Stigma (negative perceptions of people with mental health problems<br>• Approach to care (the way in which health professionals address the needs of people using services)<br>• Diagnostic overshadowing (health professionals change the way they treat someone presenting with a physical health problems because of their mental health problem) |
| Workforce - health and wellbeing | • Health and wellbeing (improve wellbeing of workforce, reduce levels of stress)<br>• High caseloads (caseloads are too high, pressure)<br>• Motivation (to stay in their job)<br>• Bullying/ blame culture (culture of bullying by managerial staff and too quick to blame) |
| Workforce - numbers | • Number of staff (increase numbers of NHS staff working in mental health)<br>• Diversity of staff (a more diverse workforce)<br>• Improvement in the way staff work (managerial practices, accountability) |
| Workforce - skill mix | • Mental health knowledge (all NHS staff to be knowledgeable about mental health issues)<br>• Continuing professional development (for all NHS staff to keep up to date with their mental health awareness and knowledge)Skilled multidisciplinary teams (need teams that are truly multidisciplinary, including peer support workers |

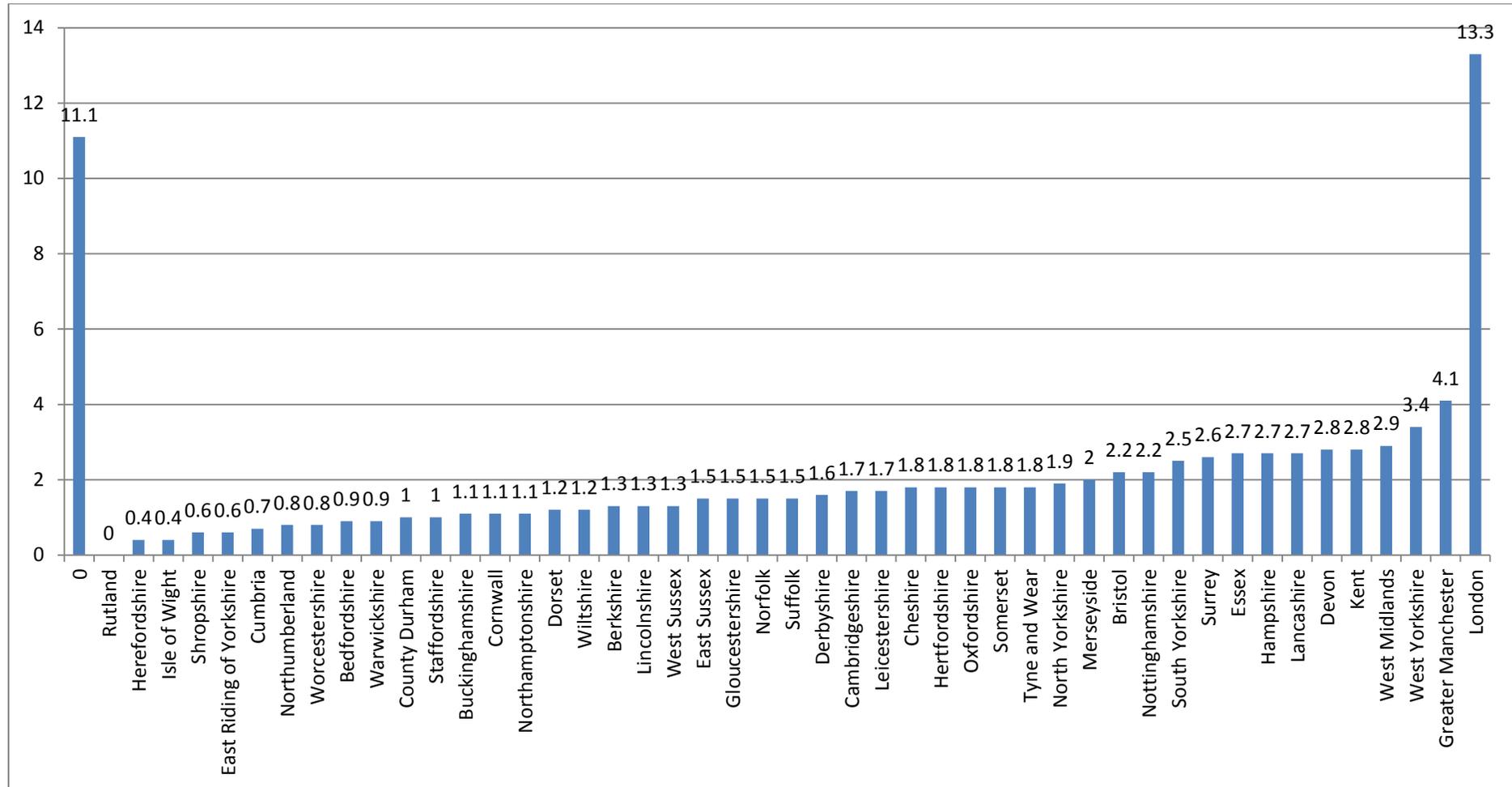**Geographical spread of respondents by local authority area**



Figure 18: Percentage of respondents by region (n=8404)

**Demographic profile of sub-sample respondents**

As with the full sample of respondents, there were more women (58.1%) than men (34.6%) in the sub-sample. Table 2 lists the number of respondents included in the sub-sample by group. This demonstrates the extra weighting given to under-represented groups.

| Table 2 | |
|---|---|
| BAME | 1531 |
| LGB | 223 |
| Transgender | 121 |
| Everyone else (i.e. White British, heterosexual) | 1028 |

The age distribution of the sub-sample is illustrated in Figure 19. There are relatively fewer respondents under the age of 15 and above 75 years.
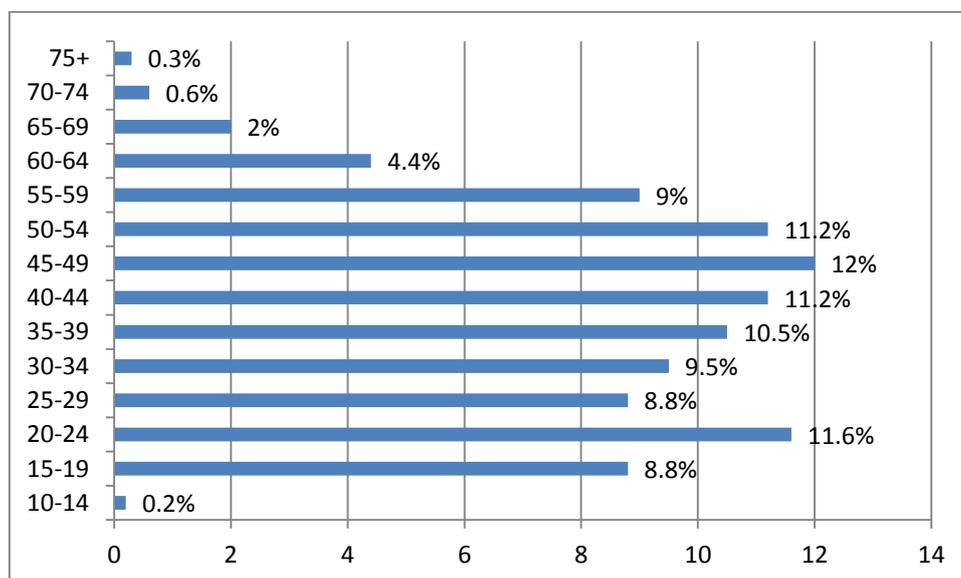


Figure 19: Percentage age distribution of the *sub-sample* of respondents (n=2409)