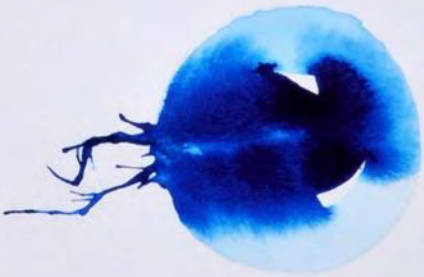
October 2019

What matters to the public in neuroscience and mental health research?

A report prepared by Ipsos MORI for Wellcome



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Cover artwork: Neurone development, Stephen Magrath. Collaboration with brain researchers at the Department of Pharmacy and Pharmacology, University of Bath.

Foreword

Wellcome is fortunate to work with some of the best international researchers tackling key problems in Neuroscience and Mental Health. As part of a review of our portfolio, we wanted to learn from a range of different stakeholders who are interested in the products of the work that Wellcome supports. Our motivation was to ask ourselves the question "what are we, and potentially the whole field, missing?" in what we currently do. The public was a key group in helping to understand how the way we work can address the priorities of stakeholders. By convening a discussion with members for the public from different UK geographies, we hoped to learn about public priorities and the way in which we can insure meaningful engagement and a deep conversation. I was delighted by the depth of insight and careful reflection that came through the series of workshops we held with the groups in Canterbury, Coventry and Leeds. The participants engaged enthusiastically with tricky issues in neuroscience and demonstrated the great value of deliberative dialogue in priority setting. We are hopeful that the model of working, the techniques we employed, and this report, will be of use to other areas of research supported by Wellcome and other organisations. While we undoubtedly still have a long way to go in producing the meaningful involvement of stakeholders in research, it was extremely positive to understand and develop techniques through the workshops. Some important common themes arose through the workshops, and we plan to explore a number of these as we develop strategic funding plans over the next few years.

I am grateful for the efforts of Lindsey Caldwell, Zaichen Mallace-Lu, Robyn Ellis from Wellcome, our partners at Ipsos-MORI, Wellcome-funded researchers who attended the workshops, and our workshop participants. I hope that you enjoy reading this report.

Dr Andrew Welchman
Head of Neuroscience & Mental Health, Wellcome

Executive Summary

This is a report of findings from a public dialogue carried out by Ipsos MORI and commissioned by Wellcome over the summer of 2019. The primary objectives were to:

1. Understand the **interests and priorities** of the public across the full range of Neuroscience and Mental Health research (NMH)
2. Test techniques to **engage the public in a meaningful deliberative dialogue.**
3. Identify opportunities for **future engagement.**

The dialogue comprised of two main elements:

1. **Face-to-face dialogue workshops** in Coventry (20 participants), Canterbury (20 participants), and Leeds (20 participants) in July and August 2019. The three workshops were reconvened so that participants came to a 3-hour session on a weekday evening then returned on a Saturday two weeks later for a day-long session.
2. A final **research summit** brought back 17 participants from across the three locations to a half day workshop in London. The purpose was to test and refine the emerging findings, to further explore areas of interest, and to gain feedback on the experience of participants with a view to thinking about public engagement more broadly.

The broad question of the dialogue, to which participants were introduced, was: **"What matters to the public in neuroscience and mental health research?'**. In developing the dialogue approach and stimulus, Ipsos MORI consulted and involved members from Wellcome's Neuroscience and Mental health team and the Public Engagement team.

Interest and placed importance

Participants came to the dialogue with **limited knowledge and understanding** of Neuroscience and Mental Health (NMH) research. However, they demonstrated an **eagerness to improve** their understanding of the brain and how it works.

Initially, participants tended to show an **interest in conditions they had direct or indirect experiences with**, and also more applied research- with most participants particularly interested in finding new treatments for diseases and disorders of the nervous system. However, as the dialogue progressed and **participants increased their understanding of NMH**, their interest widened, and they became **increasingly keen to discuss big, fundamental questions** and moved away from specific conditions that had a direct relevance to them.

As views evolved throughout the dialogue, participants became increasingly **keen to prioritise fundamental NMH questions** on brain development, which they linked to **increasing our understanding of the nature versus nurture debate.** They felt such questions needed prioritising because, although long-term, their benefits could be huge.

When discussing a number of case studies representing a range of different research projects, participants **were drawn to those with the potential to lay the foundations for discoveries across a range of conditions.** They were **also attracted to research with potential to focus on self-help and self-care**, meaning that **cost savings to the NHS could be realised** but also **alternatives therapies to drugs might be developed**. While certain areas were attractive for their reach and applicability to many, participants were quick to raise **the importance of research which might improve the lives of those with severe and life-limiting conditions**.

Other areas that participants showed interest in included personality and mood; the effects of lifestyle on the brain (diet, exercise, addiction); the detection of brain disorders and mental health conditions; brain and body interactions (e.g. hormones); brain recovery and regeneration; alternative therapies; sleep; memory and brain illness and mental health conditions.

Underlying principles

When participants were encouraged to prioritise and rank research areas over others, a range of underlying research funding **principles and values** started to emerge. The underpinning principles generated in this dialogue, **speak to those identified in other public dialogues** that have addressed strategic priorities for scientific research.

The principles that had been most commonly generated across all groups and events were often those demonstrating the values of **reciprocity, altruism, and solidarity**, and not necessarily the 'quick wins':

1. Concentrate on research that will **impact as many people as possible**.
2. Focus on **prevention** rather than treatment or a cure.
3. Prioritise research focused on **improving the quality of life** for people with **severely life limiting conditions**.
4. Consider the **potential impact to society**- both in terms of cost savings to the NHS and increasing our understanding.

While some of these principles can appear to be **conflicting** (e.g. concentrate on research that will impact as many people as possible / prioritise research focussed on improving the quality of life for people with severely life limiting conditions), their diversity, and sometimes contradictory nature, demonstrates how the public is keen for Wellcome to **prioritise a broad range of NMH research areas.** It is not uncommon for the public to suggest principles that are contradictory in nature, and we have seen this in other dialogues. However, the difference here was that we did not push participants to priorotise their principles during the main events – and only at the reconvened summit were they asked to choose between the most commonly generated.

Public engagement

The scope of the dialogue – with such an open question - was broad. While overarching principles that represent how people prioritised NMH research were identified, **the public may feel able to give more specific direction on a narrower topic**. As well, the dialogue was not framed in a way that forced people to prioritise some research areas, and discount others. In other science strategy dialogues[1] we have pushed people to make choices and therefore the findings have been more specific and focused around certain research areas.

Reflecting on the whole experience at the summit, it was clear that involvement in the dialogue had exceeded the expectations of participants, and that they found it an **interesting, engaging and enjoyable experience**. Some questioned how to be more involved in similar activities in the future, while others were left wanting to find out more. Those involved recognised that the **complex topic needed time**, and participants felt the length of the workshops was appropriate.

Participants valued the range of stimulating and reflective techniques used, as well as **the dialogue with experts** who helped participants both in terms of their thinking and their understanding.

[1] https://www.ipsos.com/sites/default/files/publication/1970-01/sri-john-innes-centre-public-dialogue-strategy-2015.pdf

While it is can be difficult in the development of materials to balance the complexity of the issues with the need to communicate succinctly to the public, the materials used did manage to achieve this balance. For example, the eight case studies that were developed represented a wide range of both fundamental and applied research in NMH research, and were commended by participants for bringing the issues to life and moving people on from discussing these issues in a broad sense to using more concrete examples. The materials can therefore act as a **useful benchmark for materials development in future**.

Conclusions and next steps

While the public recognised that Wellcome is in a unique position of being politically independent, they encouraged it **to leave areas which are already well covered**, to other organisations to fund (i.e. leaving cancer to Cancer Research UK). Some participants also felt Wellcome didn't need to prioritise areas **where we are close to finding a treatment or cure,** however this finding was not universal..

Instead, **Wellcome should focus on areas which are under-researched**, or more innovative, but importantly those addressing fundamental questions where the findings could be **widely applicable to many conditions, and that have long-term benefit**. It was also felt that the government funders should tackle the short-term priorities, while bodies like **Wellcome should have more flexibility and choice in what it decides to fund.**

In deciding what it prioritises or funds, the findings from this dialogue suggest that even where Wellcome chooses to fund research into specific conditions, **it should do so with the view of creating (and sharing) widely applicable knowledge**. For example, when talking through the case study about Huntington's disease, participants were keen for the research to take the learnings from gene editing and apply these to other genetic diseases.

There was a general **agreement that the public should be involved in decisions about science and research** and an appreciation for organisations like Wellcome who are already engaging with the public to inform decision-making.

Introduction and methodology

Wellcome commissioned Ipsos MORI to carry out a series of dialogue workshops aiming to help it in developing the portfolio on neuroscience and mental health (NMH) research and improving the organisation's means of public engagement.

While the public tend to regard the advancement of science positively and recognise the value of science research, people know very little about how research is funded or works. The complexity of scientific research can overwhelm people who feel the decision making is better left to experts, and so this dialogue was delivered in an accessible way that helped people understand the workings of science research so that they felt informed and able to provide their views.

Dialogue aims and objectives

This dialogue aimed to help Wellcome enhance its NMH research portfolio by involving the general public in identifying and discussing their priorities. In addition, it aimed to provide key insights around how to engage the public in science and health research.

Overall, there were three main dialogue objectives, and a number of sub-objectives:

1. Understand the interests and priorities of the public across the full range of NMH, and more particularly:
    a. Identify which areas of NMH research the public find most and least interesting
    b. Identify which areas should be given the highest priority for funding
    c. Find out whether the public is more interested in the answers to fundamental biological questions (e.g. how does the brain work?) or in finding new treatments for diseases and disorders of the nervous system

2. Test techniques to engage the public in a meaningful deliberative dialogue:
    a. Explore, test and use dialogue and engagement approaches that enable our ambition to gain rich and contextual insights that are informative to Wellcome's NMH portfolio review
    b. Understand how this process could be repeated, for example by other science teams in Wellcome, to identify the interests and priorities of the public in areas of science outside NMH
    c. Understand if/how the process could be scaled up to include more participants, locations or subjects

3. Identify opportunities for future engagement:
    a. Build an awareness of the public's understanding of NMH through the exercise itself,
    b. Identify opportunities for further public engagement initiatives

Why a dialogue?

One of the key priorities for Wellcome's engagement team is to better understand **what matters** to the public in NMH research. While the public tend to positively regard the **value of science and research**, it can be challenging for people to separate what they are interested in for **society as a whole**, from what interests them due to **personal experiences**. The public often place importance on all areas of science research [2], finding everything interesting and appreciating the potential benefits for all, which can make getting decisive outcomes challenging. **Understanding the brain is especially important to the public**. In 2016, Wellcome's Monitor survey of the public found 45% of the participants put neuroscience in their top three areas of interest, with mental health top of specific interests in medical research at 55%[3].

Through a variety of carefully designed exercises that aim to both inform and challenge participants, and with the involvement of experts, a dialogue allows for a **more nuanced level of discussion**. It forces participants to place greater weight on certain areas than others and encourages them to reflect on their reasons for doing so. Engaging in a dialogue is also an effective and valuable way to **engage and empower participants** by helping them to access, use and respond to health research and innovation-– one of the key aims of Wellcome's engagement strategy. Overall, by encouraging participants to **reflect on their own experiences** and **spontaneous views**, this dialogue enabled us to go beyond these surface level preferences, and formulate the **wider values and principles** driving people's decision-making. Another benefit of this dialogue was to ensure that people from lower socio-economic groups and ethnic minorities -who have been found to value health research slightly less and have less confidence in it than other groups - were included in the research so their **voices would be heard**.

The role of experts

In order to understand what matters to the public and their priorities for NMH research, we needed to help participants think about the less apparent links between research and public benefit, particularly in terms of fundamental or applied research. To be able to provide context and an environment that enables participants to go beyond the obvious associations, **information sharing from experts** at the various events was essential.

To ensure that the information given to the dialogue participants was balanced, we involved a number of **Wellcome-funded neuroscientists** (who will be referred to as 'experts' in the report) in different activities at the workshops and post-research summit.

The experts came from a number of fields and institutes (see Table xx below) and were tasked with **educating** the participants about different areas of NMH research, giving examples where asked and **prompting** with further thoughts from their own experience.

Overall, the experts were there as an **integral part of the participants' dialogue journey** and played a key role not only in answering their questions, but also **challenging their views** and pushing them to consider the wider

[2] Public Attitudes to Science Survey, 2014, https://www.ipsos.com/sites/default/files/migrations/en-uk/files/Assets/Docs/Polls/pas-2014-main-report.pdf

[3] https://wellcome.ac.uk/sites/default/files/monitor-wave3-full-wellcome-apr16.pdf

applications of research. In doing so, they enabled the participants to fully engage with the topic areas, creating lively and informed conversations that were able to both broaden or delve deeper into different NMH research topics. Furthermore, they allowed for a two-way dialogue to take place between them and the participants - creating a unique opportunity for them to converse with, and learn from, the general public.

Table X: Experts who attended and contributed at a dialogue event

Name	Organisation	Event location
Dr Alice Milne	University College London	Canterbury event 1
Dr André Marques-Smith	University College London	Canterbury event 2 London post-research summit
Dr Manuel Spitschan	University of Oxford	Leeds event 2
Dr Marwa El Zein	University College London	Coventry event 1
Dr Philip Coen	University College London	Leeds event 1
Dr Richard Rosch	King's College London	Leeds event 2
Dr Lindsey Caldwell	Wellcome	Canterbury events 1 and 2 Coventry events 1 and 2 London post-research summit
Dr Louise Marshall	Wellcome	London post-research summit

The role of the Wellcome's engagement team

The involvement of Wellcome staff consisted of:

- providing guidance in the drafting of the research materials – notably by picking, choosing and writing up a number of case studies of NMH research which were discussed by the participants.
- giving information about their work and probing participants throughout the dialogue events.

Methodology

The dialogue was carried out over three locations (Canterbury, Leeds and Coventry) and comprised of:

1. An evening dialogue workshop in each one of the locations. This was a preliminary information sharing experience where we gathered participants' spontaneous views on science and NMH research and brought them up to speed and to a baseline level of knowledge. This gave a good opportunity for participants to go away and reflect on what was covered.

2. A reconvened day-long workshop two weeks after the initial meeting. This created a more informed discussion between the participants and NMH experts - which allowed the exploration of NMH areas in a greater depth than would have been possible at the first event.

3. A final post-research summit in London involving a third of the participants from across the previous events. Having given the participants time to absorb the information, the summit provided the opportunity to consolidate views and opinions, and delve further still into their priorities.

During each of the evening and Saturday workshops, participants were divided, by tables, into two age groups to allow us to analyse whether attitudes towards NMH research differed across and between the different age groups. The broad question of the dialogue, 'What matters to the public about neuroscience and mental health', was introduced to participants at the start of the first event and revisited throughout the workshops. Exercises were used for various purposes, some as ways of presenting information, others to gather participant views, and the majority intended to push the participants into thinking beyond their usual understanding and to consider the complexity and intricacy of NMH research.

Recruitment and sample composition

A total of **sixty participants,** 20 per location, were recruited and 17 attended the post-research summit.

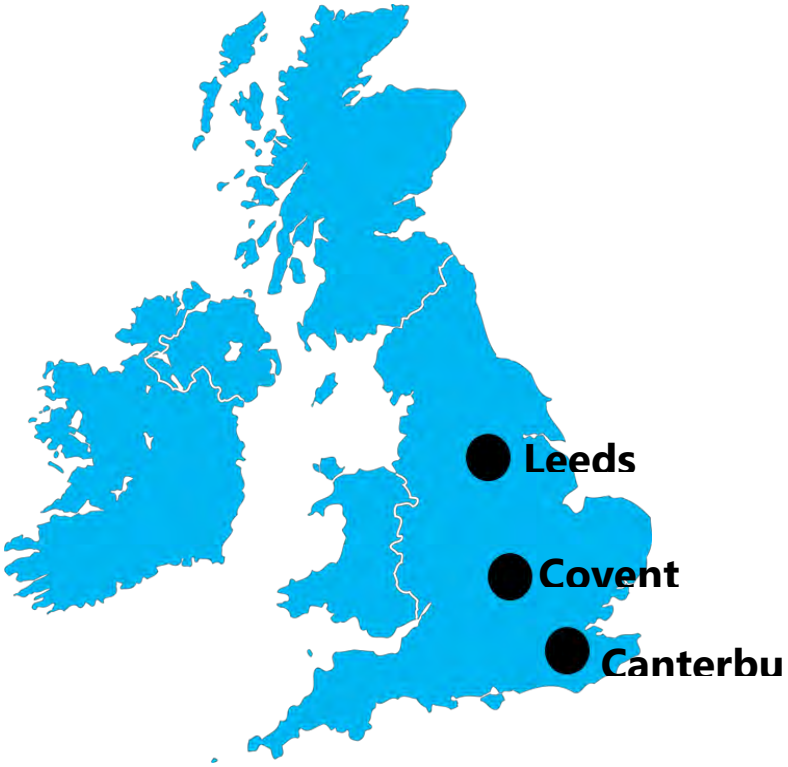
Participants were recruited to reflect the populations of each of the three areas, with a sample that included a quota for age, gender, ethnicity, working status and socio-economic grade. However, in to order to make sure the views of those groups were captured, all participants in Leeds were recruited from **Black, Asian and Minority Ethnic (BAME) communities**. We thought it was important to do so as research has shown that ethnic minorities are more likely value health research slightly less and have less confidence in it than other groups[4]. They also tend to be more cautious about accepting the idea that scientific and health research may have a benefit to wider social groups[5]. It was therefore critical to try and explore the role of ethnicity in perceptions of social benefits of NMH research.

It is also worth noting that all the participants in Canterbury lived in a rural or semi-rural area.

[4] HRA and NIHR survey: There was also a significant difference by ethnicity with 84% of white respondents rating health research as very important compared with 75% of ethnic minorities. https://www.hra.nhs.uk/about-us/news-updates/survey-finds-strong-public-support-health-research/

[5] https://www.ipsos.com/sites/default/files/ct/publication/documents/2019-04/public-dialogue-on-genomic-medicine-full-report.pdf

Figure 1.1: Locations of the groups



Out of scope

As part of the dialogue aim and objectives, there were certain areas within NMH research that we decided to keep out of scope, namely depression, anxiety and dementia. Dementia was kept out of scope because it is a big focus of initiatives for other research funders such as the Medical Research Council, the Dementia Research Institute, Alzheimer's Research UK, etc. Depression and anxiety were kept out of scope because Wellcome has just established those conditions in young people as a priority area and committed additional funding earlier this year[6].These areas were still discussed in terms of spontaneous views of what was interesting or important to the participants, but they were guided away from focussing too much on them.

Report plan

This report is divided into two main sections. The first one explores our findings around participants' interests in NMH research, how these evolved throughout their dialogue journey, and how priorities and principles underpinning their decision-making emerged. The second section reflects on the techniques used to engage the participants in a meaningful deliberative dialogue and identifies opportunities for future engagement.

[6] https://wellcome.ac.uk/what-we-do/our-work/mental-health-transforming-research-and-treatments

Reading this report

Qualitative research approaches (including public dialogues) are used to shed light on why people hold particular views, rather than how many people hold those views. The results are intended to be illustrative rather than statistically reliable. Given the qualitative nature of the data collected from the dialogue, this report aims to provide detailed and exploratory findings that give insight into the perceptions, thoughts and feelings of people, rather than statistical evidence from a representative sample. It is not always possible in qualitative research to provide a precise or useful indication of the prevalence of a certain view, due to the relatively small number of participants generally involved (as compared with the larger respondent bases involved with quantitative studies). So, the views of proportions of the qualitative group should not be extrapolated to the population at large. Therefore, we use different analysis techniques to identify how important an idea is. This report states the strength of feeling about a particular point, rather than the number of people who have expressed that thought. Having said this, is it sometimes useful to note which ideas were discussed most by participants, so we also favour phrases such as "a few" or "a minority" to reflect views which were mentioned infrequently and “many” or “most” when views are more frequently expressed.

Interests and priorities in Neuroscience and Mental Health research

This section summarises the findings around participants' interests and priorities in NMH research- which emerged from a range of activities carried out throughout the reconvened events and the post-research summit. In doing so, it explores how these evolved throughout participant's dialogue journey.

First, it looks at participants' spontaneous views on science- understood in a broad sense- before moving on to neuroscience and mental health more specifically. It then outlines participants' interest levels in both fundamental and applied research. Finally, it explores, through the discussion of Wellcome-led and other NMH research proposals and case-studies, how participants' views evolved, and how priorities and principles underpinning their decision-making emerged.

Spontaneous views about science, the brain and mental health

In a public dialogue, the set of issues to explore are often complex and the public will not necessarily have thought about these at great lengths previously. Therefore, the process involves the provision of information, and views from a range of perspectives, to enable participants to become adequately informed[7]. A common starting point is to capture uninformed or spontaneous views on the topic. This allows for any misperceptions to be aired, and later dealt with, as well as for a baseline of participants' views and knowledge levels. In the analysis stage, we are able to use these early discussions to help us assess how and why views changed as people become more informed.

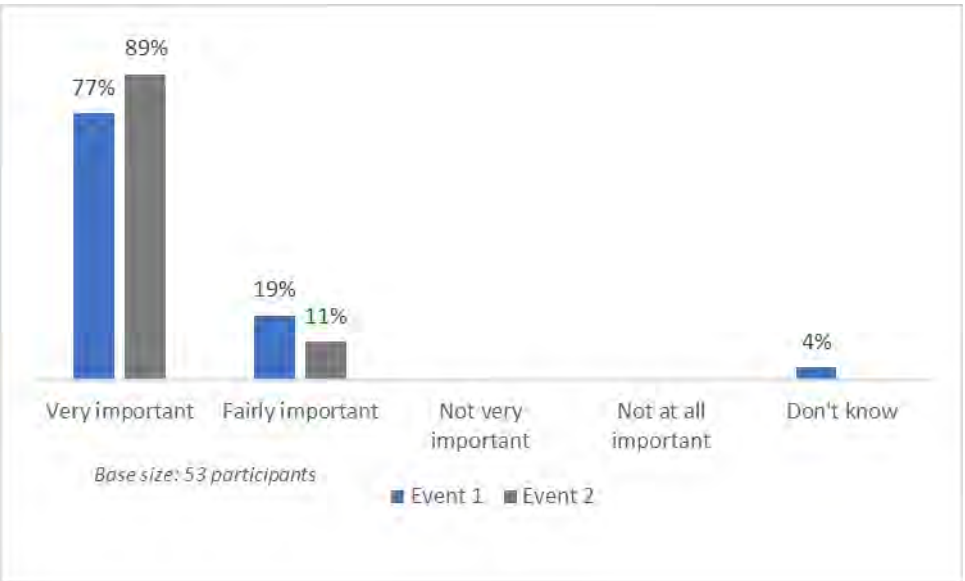
At the beginning of the evening workshops, as a warm-up exercise, participants were asked their thoughts on the following questions: When you think about science, what words come to mind? What difference types of scientific research have you heard of/are you interested in?

Overall, participants across all groups tended to conceptualise science in abstract terms but also viewed it extremely positively, linking it to advancement and progress. There was widespread acknowledgement across all groups that scientific research had the potential to improve quality of life, with such views prompting some participants to think about its practical applications and benefits.

Tracking questionnaires were given to participants to fill out both at the start of the dialogue (beginning of the evening workshop) and at the end of the dialogue (end of the Saturday workshop) to track their interest and understanding of NMH. Participants were asked about the importance of funding and supporting NMH research. At the start of the dialogue, 77% of those who responded reported that it is 'very important' to do this, which rose to 89% by the end of the dialogue.

[7] http://sciencewise.org.uk/wp-content/uploads/2018/09/Sciencewise-Guiding-Principles-August-2018.pdf

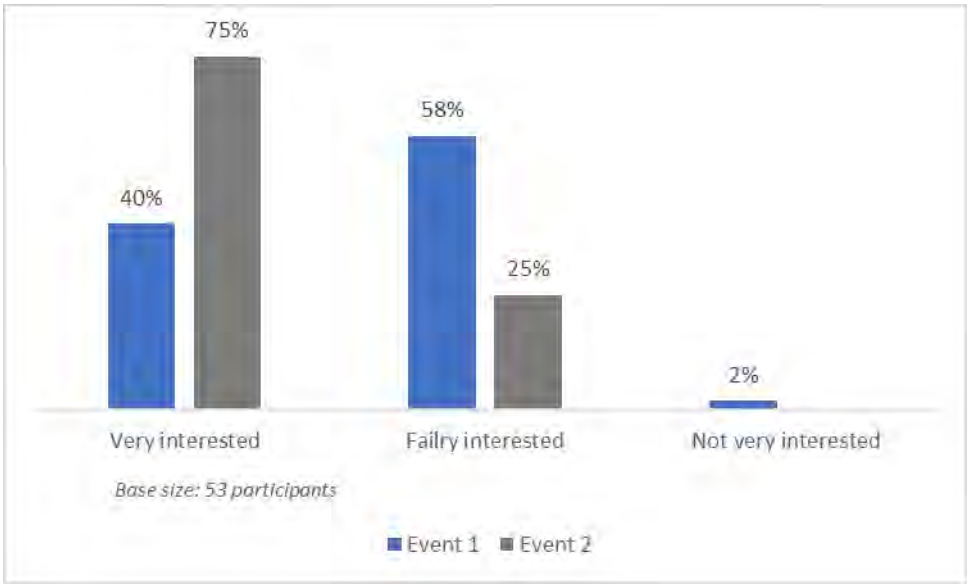
Table 1.1: Tracking questionnaire responses to 'How important do you think it is to fund and support neuroscience and mental health research?'



Initial understanding of the brain and neuroscience

In the tracking questionnaire, participants were asked how interested they were in the brain and how it works. At the start of the dialogue (beginning of the evening workshop), 40% of those who responded reported that they were '*very interested*', and this rose to 75% by the end of the dialogue.

Table 1.2: Tracking questionnaire responses to 'How interested are you in the brain and how it works?'



When prompted more specifically on the brain- what it is, what it does, what is it responsible for, and how it affects one's physical and mental wellbeing (and vice versa)- participants were able to demonstrate their levels of awareness and knowledge about the brain and neuroscience, but had a limited understanding of how the brain works. In doing so, they made the following observations:

- how **no brain is the same**- this was raised by several participants and prompted some discussions on the nature versus nature debate- a theme that was recurrently mentioned throughout the different events, and across all groups.

- how **brain health and wellbeing**- both mental and physical- are closely **interlocked**, and how they influenced each other. In discussing this, participants demonstrated an understanding of what one should do to **keep their brain 'healthy'** – and how certain lifestyle choices (eating well, sleeping enough and exercising), could not only benefit overall wellbeing, but also have a positive effect on the brain.

Understanding of neuroscience and mental health

In spite of having discussed the brain and its functions, when asked to reflect on mental health and how it relates to neuroscience, participants did not naturally make the connection between mental health and neuroscience and the brain. Instead they were drawn to discuss:

- mental health in relation to **access to services**, **children** and school education, and **social media** rather than in relation to research.[8]

- out of scope areas such **depression** and **dementia**, because of their prevalence, and because most participants had some personal experiences relating to those conditions.

- the importance of **talking about mental health**, and how while it was increasingly less of a taboo among young people, older generations were less inclined to talk about their feelings- although there was an acknowledgment this was slowly changing.

It is important to note that, throughout all the events, **talking about the brain rather than 'mental health'** was often a more effective way to get participants to think of and understand **the wide scope of NMH research**.

All in all, it appears that **personal applicability and relevance** were the key drivers of initial/ **uninformed interests** relating to specific areas of NMH research. Participants tended to pick conditions they had a direct or indirect experience with, such as dementia, personality disorders, anxiety, or autism, because these affected family members and/or people they knew.

Initial views on applied versus fundamental research

During the evening workshop, participants were explained the difference between **fundamental and applied research**, and encouraged to reflect on whether they were more interested in the answers to fundamental questions or in finding new treatments for diseases and disorders.

Although participants' initial understanding of fundamental and applied research was low, they were able to **quickly grasp the differences** between both concepts and were able to recognise the pros and cons of each.

[8] It is possible that, because the coverage of new stories around mental health have significantly grown in recent years, participants were particularly keen to discuss those issues as they had already formed opinions about them, and were keen to bring those up and/or felt more confident to discuss those in a group setting.

At this point in the dialogue, when people were still early in the journey, participants across both age groupings were more likely to think **applied research was more interesting and important** than fundamental research. This was often linked to the point raised above that, more often than not, participants were keen to explore areas related to **specific conditions which had direct relevance to them.**

"The basics of how a brain works don't impact me, but what causes strokes and how you can impact them would be more interesting". (Male, Coventry evening event).

However, such views were not uniformly shared, with some participants especially keen to understand wider questions around the brain, and believing both fundamental and applied research went hand in hand.

"I think understanding first, and then you work from there. There's no point in developing a drug and then the woman dies, because you don't know from scratch what it's all about". (Female, Leeds evening event).

All in all, participants were somewhat split: a minority thought that understanding the brain itself was key, while most of them were initially more interested in finding new treatments for diseases and disorders of the nervous system. Yet it is worth noting that, as participants progressed through their dialogue journey, their interest in the fundamental questions of NMH research increased.

Participant views on Wellcome-led research proposals

While the evening groups were mainly designed to **increase participants' levels of understanding of NMH research**, Saturday workshops aimed to uncover which **topics particularly caught their interest**, why they did, and which ones **they wanted to see being prioritised** by Wellcome.

This was mainly facilitated through the discussion of eight case studies covering a wide range of NMH research areas- both applied and fundamental (see the Appendix 1.8 for more details about each case study):

1. **How do we remember past experiences?** Understanding how memories are stored in the brain.
2. **How can we predict who will lose their sight?** Using computers to help predict when patients will lose their sight.
3. **Does mindfulness work?** Generating evidence for the effects of mindfulness.
4. **Which part of the brain controls sleep?** Identifying the switch in the brain sending us to sleep.
5. **How can we stop chronic fatigue after a stroke?** Understanding why people experience fatigue after stroke.
6. **How do emotions affect the body's immune system?** Understanding how emotions affect the immune system's ability to fight disease.
7. **How does the brain develop?** Understanding how the brain develops, and how this is affected by genetic and environmental factors.
8. **How can we treat Huntington's disease?** Trialling a treatment for Huntington's disease.

Participants had the opportunity to discuss the case studies with NMH experts who were briefed not only to provide them with additional information, but also to challenge them and make them contemplate the wider implications of each research area. This is typical of public dialogue.

Interest versus importance

Throughout these discussions, participants were encouraged to reflect on what they thought was interesting, while also considering what they thought was important- to them, to people they know and care about, to groups of people with specific conditions, and to the wider society.

Overall, it transpired that interest and importance in NMH research did not necessarily go in hand in hand. What interested participants was often framed by personal experiences and relevance, while considerations of what was important and what should be prioritised were linked to the breadth and depth of the impact of a research area- - whether this was about specific groups of individuals or wider society.

It is also worth noting that some differences emerged between the different age groupings- with older groups appearing slightly more interested in the research which could be classified as tangible and applied research, and the younger ones more interested in fundamental science and the overall understanding of the brain. However, views evolved and shifted as importance was taken into consideration, with participants across both age groupings keen to prioritise case studies relating to vast fundamental NMH questions around the role of genetic and environmental influences on brain development. Underpinning principles

Asking participants to discuss the importance and interest of each case study was an effective way to get them to reason and reflect on different topics, and allowed facilitators to determine which key factors and considerations shaped their decision-making processes when doing so. It was important for Wellcome to understand not only what interested participants, but why they thought the way they did.

Through the discussions of the case studies, a range of underlying research funding principles and values expressed by participants started to emerge (Figure 1.2 below). And while these were not always explicitly formulated by the participants, they were captured by the facilitators and sense-checked during the workshop.

The top five principles (1-5) were reported and referred to repeatedly across all groups in all three locations, however not necessarily in this order or top of the list of principles across groups. As participants generated the principles, they were recorded by the facilitators during the discussion of case studies and participants were not asked to order or pushed to prioritise them. The remaining principles (6-15) were reported in some groups but not others. Principle 14 (Do not prioritise research that will lead to the development of expensive drugs and treatments that people will never be able to access), was not necessarily relevant to the case studies, or research areas discussed, however was an important consideration for dialogue participants.

Figure 1.2 Participant generated underpinning principles

At the post-research summit, participants were presented with the five top principles that had been most commonly generated across all groups and events. Overall, participants agreed those matched what they discussed, while also acknowledging some principles complimented or contradicted each other.

"It was a very difficult conversation because we wanted to help the masses and make sure the research impacted as many people as possible, but some of the conditions were so life limiting that it felt difficult not to invest research there". (Female, London post-research summit).

Participants were then asked to single out the principle they thought was the most important. Interestingly, participants voted quite differently across all groups- this might because different conversations were carried out and different topics brought up at each table. On the whole, participants singled out three main principles at this point:

1. consider the potential impact to society- in terms of cost saving to the NHS, and increasing our understanding;
2. focus on prevention rather than treatment or a cure; and
3. prioritise research focused on improving the quality of life for people with severely life limiting conditions.

By picking the three principles at the summit, participants demonstrated how they were less focused on themselves and people they knew, and rather wanted to prioritise NMH research impacting specific groups affected by severe conditions, or the wider society- and in doing so demonstrated values of reciprocity, altruism, and solidarity.

Participant views on case studies

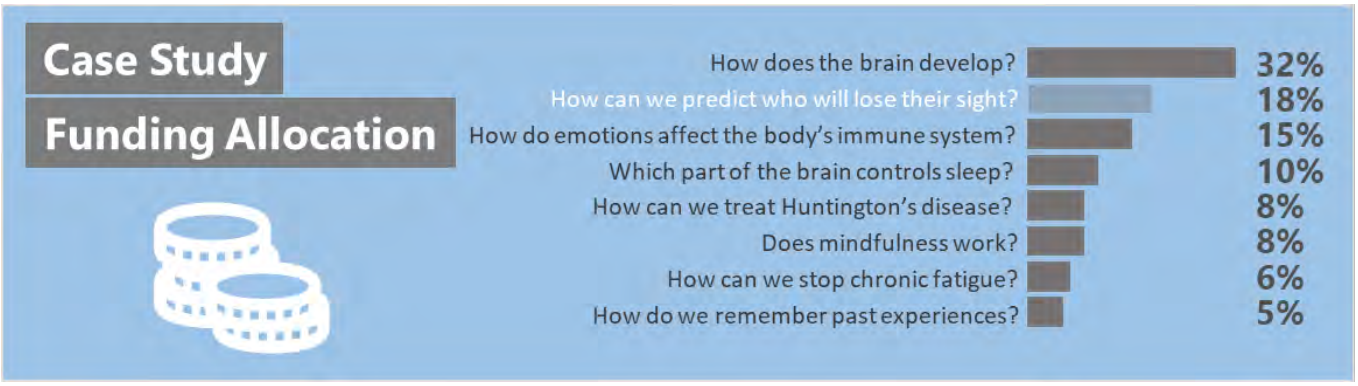
As mentioned above, the core activity of the Saturday workshops was the dialogue with the experts around eight case studies. These were chosen by Wellcome to represent the breadth of NMH research, in terms of scale (genetics to cognitive neuroscience), approaches (studies involving AI, people, animals etc), and range (fundamental and applied). To avoid any bias, the order that the case studies were presented in was rotated across the three events.

For each case study, participants were asked to reflect on what interested them about the research, what was less appealing, who they thought the research would benefit, whether they thought the it would be helpful, and which other studies they would like to see within the relevant areas. Throughout this exercise, participants were challenged, probed and asked to broaden their thinking while they shared their thoughts and engaged with one another.

At the end of this activity, participants were asked to complete a budget/token allocation task: each participant was given five stickers representing their 'research budget'. They were asked to decide which case studies they wanted to fund and could distribute their tokens as they wished - i.e. allocate all five for one case study or spread them across several. Each case study was ranked according to budget allocation and this was then

compared to the mapping of the case studies completed in the previous exercise, described above. The rational for this exercise was to assess whether giving participants **a sense of responsibility** over which areas of NMH research to fund would somewhat alter their decision-making processes.

Figure 1.4: Allocation of stickers per case study



(Please note that the title of this case study was amended after the Canterbury workshop from "How can we predict disease progression?" to "How can we predict who will lose their sight?". It appeared that this case study ranked well in Canterbury because participants focused on the prediction of diseases and conditions, rather than on just on age-related macular degeneration).

Participants commented on the **difficulty of this task** as they were completing it as they felt all the case studies were both interesting and important. Some even described it as 'stressful', suggesting that it was not easy to choose and therefore their prioritisation required **careful consideration**. Interestingly, although the mapping and budgeting exercises were **framed differently** (i.e. in the first one, the participants were guided by their own opinions and values, while in the latter one participants were asked to reason as if in charge of the Wellcome's budget for NMH research), the ranking of the case studies in both exercises were **more or less similar** across all groups but one.

This suggests that **participants formed distinctive opinions** about which areas of NMH research to prioritise throughout **their dialogue with the experts** and these did not change when given the responsibility to evaluate the case studies individually (rather than as a group).

Overall views on the case studies

On the whole, it appears that participants' thought processes were clearly guided by **the scale of impact** above anything else (Principle 1). It is also worth noting, perhaps surprisingly, that when prioritising the different case studies, **timescale did not seem to matter that much**. Participants across all groups, and irrespective of age, were able to project themselves far into the future and think about how NMH research could **benefit future generations rather than their own** (Principle 13).

Yet, participants' interest and prioritisation were often also driven by **personal applicability**- i.e. whether they knew, or knew of, somebody affected by a certain condition. On the other hand, the prioritisation of some case studies over others was driven by **their potential impact**- on a group of affected people, the overall population and/or the wider society. For instance, as shown in Table 1.3 below, the case study *'How can we stop chronic fatigue after a stroke'* ranked relatively well among the younger participants in Canterbury because somebody

in that group knew somebody affected by the condition. They could express to the rest of the participants in **relatable and personable terms**, how severe and alienating its effects were- which the rest of the group **empathised with**. Conversely, whilst one of the groups in Leeds acknowledged that chronic fatigue was important in terms of impact for those suffering from it, they did not rate it as important or interesting as they explicitly stated they did not know anybody affected.

Table 1.3: Case studies' ranking across all groups

Group	How do we remember past experiences ?	How can we predict who will lose their sight?	Does mindfulness work?	Which part of the brain controls sleep?	How can we stop chronic fatigue after a stroke?	How do emotions affect the body's immune system?	How does the brain develop?	How can we treat Huntington's disease?
Canterbury- younger	8th	1st [9]	6th	7th	4th	2nd	2nd	4th
Canterbury- older	7th	1st [10]	5th	7th	6th	4th	3rd	1st
Coventry- younger	7th	6th	5th	2nd	4th	3rd	1st	7th
Coventry- older	8th	2nd	6th	4th	7th	5th	1st	3rd
Leeds- younger	3rd	4th	3rd	4th	7th	2nd	1st	8th
Leeds- older	3rd	2nd	4th	6th	8th	7th	1st	5th

Specific views on the case studies

Participants' views, the underlying principles they used when discussing each case study, and the additional questions raised by participants are summarised in Table 1.4 below.

The case study on "*How does the brain develop?*" was clearly the one area of NMH research that the vast majority of participants were interested in and wanted to see prioritised over others. Yet it is important to note that interest

[9] Please note that the title of this case study was amended after the Canterbury workshop from "How can we predict disease progression?" to "How can we predict who will lose their sight?". It appeared that this case study ranked well in Canterbury because participants focused on the prediction of diseases and conditions, rather than on just on age-related macular degeneration.

[10] Idem

in the case study was not apparent straight away, with some participants struggling to conceptualise how such research could be beneficial:

> *"With this research, it seems that this is the result of scientists being bored."* (Female, Canterbury Saturday workshop)

Yet as the dialogue progressed, a general consensus emerged that this was the one key research question that needed looking into, and that gaining a better understanding of the brain and how it works, was of utmost importance because of the potential for a ripple effect – Principle 6 (see Table 1.4). While the participants showed a particular interest in deliberating the nature versus nurture debate throughout the dialogue, it was through discussing this case study that they became most animated.

Overall, when participants were able to think in broader terms and conceive the wider impact of a case study, it tended to rank well- which was the case for *"How does the brain develop?"*, *"How do emotions affect the body's immune system?"*, and "*How can we predict who will lose their sight?*" (but only when participants framed it in terms of disease progression rather than just AMD). NMH research areas which ranked less well were those which were perceived as being mainly focused on a single condition, with participants struggling to see the wider applicably. This was the case *for "How can we treat Huntington's disease?"*, and *"How can we stop chronic fatigue after a stroke?"*, in spite of participants acknowledging the severity of those conditions and the negative impact on those who have them (Principle 3).

Another point worth noting is that discussions throughout the dialogue – and in particular when discussing the case studies - demonstrated how participants were often drawn to alternative therapies (Principle 9). For example, when discussing mindfulness, it was felt such therapies were sometimes preferable to taking medication, especially when it came to mental health because participants believed that (a) some medication could have unknown and/or undesirable side effects, and (b) such treatments could help the NHS cut costs in the long run (Principle 4).

> *"Yes, and having the natural therapy involved is a lot better because instead of being given lots of medicine. It's much more integrated into your whole lifestyle."* (Male, Canterbury Saturday event)

Finally, case studies relating to issues that participants assessed as non life-threatening – *"Which part of the brain controls sleep?"*, and "*How do we remember past experiences?*"- did not score as highly compared to others. Nonetheless, they generated enthusiastic discussion and prompted participants to raise a number of questions (see Table 1.4).

Table 1.4: Overview of the discussions around the case studies

	General thoughts	Formulation of principles	Additional questions raised
How does the brain develop?	➢ Generated the **most interest** among all groups ➢ Participants linked this to the **nature versus nurture** which was debated throughout the dialogue ➢ Participants viewed this as **the groundwork for a lot of conditions** (such as autism, schizophrenia and epilepsy and so on)- in terms of finding new treatments and increasing our understanding. ➢ Raised discussions around **the lifespan of the brain.** *"I think brain development would be the best for general knowledge, and with that information it might speed up the other case studies"* (Male, Coventry Saturday event)	Principle 1: Concentrate on research that will impact as many people as possible Principle 2: Focus on prevention rather than treatment or a cure Principle 4: Consider the potential impact of research to society – in terms of cost saving to the NHS, and increasing our understanding Principle 6: Focus on areas that can have a 'ripple effect' Principle 11: Focus on research the public is interested in/ thinks is important	➢ How can siblings differ from one another despite growing up in the same environment? ➢ What happens in the womb? ➢ How does brain development impact on adult life? ➢ Why are some people good at mathematics and others aren't? ➢ Does the brain get weaker as you get older? Why does the brain degrade? ➢ Do people develop certain conditions such as autism or are they born with it? ➢ What are the triggers in schizophrenia?
How do emotions affect the body's immune system?	➢ Consensus that this an important issue to look at, despite the benefits of the research to be seen in **a distant future**. ➢ Has the potential to have **big financial repercussions** as savings could be made on treatments if people focus more on **self-help and care**. ➢ Raised some questions around how much is within one's control. One participant questioned the connection between emotions and illness, and this could place the blame on people for getting sick. **Framing such issues the right way** is important so people do not feel they are at fault. ➢ Also raised some questions around the **practicalities** of this research e.g. how do you measure people's emotions and outlook on life?	Principle 1: Concentrate on research that will impact as many people as possible Principle 4: Consider the potential impact to society- in terms of cost saving to the NHS and increasing our understanding Principle 8: Prioritise research that enables self-help and self-care Principle 11: Focus on research the public is interested/ thinks is important Principle 15: Concentrate on ethical research	➢ Are people more susceptible to disease/illness if they have a negative outlook on life? ➢ Do negative thoughts make tumours grow? ➢ What in your brain heals tumours? ➢ Why does being negative take your energy away? ➢ Is this passed through DNA? ➢ What is the role of placebo? ➢ Can we do things to improve our immune system? ➢ Does our emotional state make our brain more likely to get addicted to certain things?

Which part of the brain controls sleep?	Participants found it interesting across all groups but **disagreed on its importance**: ➢ On one hand, the case study was seen as **not leading to a treatment or cure.** ➢ On the other hand, participants agreed of **its wide reach** given that this concerns everybody, and we all sleep, so could benefit. Discussions around sleep mainly revolved around: ➢ Its importance and **its positive effects**, with participants linking sleep with mental wellbeing and mindfulness. ➢ **Dreams** and their importance and significance ➢ The relationship between sleep and **productivity** ➢ The relationship between sleep and **lack of functionality** ➢ The relationship between sleep and **illness** (and how illnesses can impact one's sleep and vice versa) *It's more about interest. If I read through these it would drop to the bottom of the pile because it is about learning more about something rather than fixing a problem.* (Female, Leeds Saturday event).	Principle 1: Concentrate on research that will impact as many people as possible Principle 6: Focus on areas that can have a 'ripple effect' Principle 12: Consider areas that will impact on quality of life	➢ Can you learn while sleeping? ➢ What is the role of the subconscious? ➢ Why do some people wake up grumpy? ➢ Why does light keep you awake? ➢ What is the effect of working night shifts on your brain? ➢ How and why do certain conditions like schizophrenia and Parkinson's affect sleep and vice versa?
How can we predict who will lose their sight?	➢ Participants were often eager to talk about the importance of **the wider implications** of being able to predict diseases, but not necessarily just age-related macular degeneration. ➢ They were keen to emphasise the **severity of the condition,** and how eyesight was directly interlocked with independence and quality of life. **Older groups** were more likely to find the case study interesting and important than the younger groups. This might be because the condition is **age-related**.	Principle 3: Prioritise research focused on improving the quality of life for people with severely life limiting conditions Principle 6: Focus on areas that can have a 'ripple effect' Principle 12: Consider areas that will impact on quality of life Principle 13: Do not prioritise research targeted at certain generations over others	Many of the questions raised were around the condition itself, due to low awareness of this- ➢ Is the condition hereditary? ➢ Could it be caused by environmental factors? ➢ How does it differ from glaucoma? AI was also discussed in that context: ➢ Would it be better to rely on individuals rather than AI to treat such conditions?

How do we remember past experiences?	➢ Participants often felt this topic was **more interesting than important**. They didn't feel this was a 'game changer'. ➢ They were keen to talk about their **own personal experiences**, with some wondering why they remember certain things and not others. ➢ That view wasn't uniformly shared as some brought up **specific conditions affecting the memory**, such as dementia and PTSD, and could envisage the research's potential benefits.	Principle 4: Concentrate on conditions and illnesses that are experienced for longer period of times throughout a lifetime	➢ Why does our memory deteriorate over time? ➢ How do negative memories affect the brain? ➢ Why do we block certain memories? ➢ Why do we remember insignificant things? ➢ Why if you had an accident, you can't remember how it happened?
How can we treat Huntington's disease?	➢ **Rated highly** both in terms of importance and interest. ➢ The **severity** of the condition, and the fact **that the strive to find a solution was well underway**, meant that participants wanted to see this research being funded – even though they weren't directly affected by the condition (and many had not even heard of it at the before the dialogue). ➢ High interest in the ability to **silence genes** and its potential to be understand, and even treat other genetic conditions.	Principle 3: Prioritise research focused on improving the quality of life for people with severely life limiting conditions Principle 7: Focus on conditions that would otherwise been overlooked Principle 10: Focus on areas where there is evidenced potential for finding a definite and tangible impact	➢ How do you silence a gene? ➢ If you silence the Huntington's gene, why can't we silence others? Why can't you silence the autism genes? ➢ What's the differentiation between diseases, conditions, and disposition? ➢ How long can you silence a gene for? Can you un-silence/restart a gene? ➢ Could you create a DNA bank for people? ➢ If they can silence a gene, can they restart a gene? ➢ Is gene silencing ethical?
Does mindfulness work?	➢ Most participants tended to agree on mindfulness and **its potential positive impact on mental health**- with only a handful questioning its benefits. ➢ While acknowledging mindfulness was important and could be used as an **alternative therapy to drugs**, participants also believed research in this area was not necessarily a	Principle 4: Consider the potential impact to society- in terms of cost saving to the NHS and increasing our understanding Principle 8: Prioritise research that enables self-help and self-care	➢ Can practicing mindfulness replace the need for taking certain medications? ➢ What causes chemical imbalances in the brain and what is the role of mindfulness in rebalancing them? Participants didn't raise many questions about this case study as most believed its **benefits** had

	priority as many believed the benefits of mindfulness had been long proven. ➢ Participants were actually keener to talk about how it should be **promoted among children**, especially teenagers and how schools could be the ideal platform to do so. *I think it would be pointless to spend so much money on that to find out how it works rather than doing research to just find out that it works."* (Female, Canterbury Saturday event)	Principle 11: Consider research aiming to develop alternative therapies rather than the development of drugs	already been long proven. Most if their questions revolved about the **practicalities of practicing mindfulness** and implementing it in schools, universities or workplaces.
How can we stop chronic fatigue after a stroke?	Participants tended to agree this was important, and importance was often linked to: ➢ **the severity of the condition**- and how the effects of the condition could impact not only the person suffering, but also people around them ➢ the **personal relevance** to participants- with many knowing people having experienced a stroke and/or chronic fatigue.	Principle 3: Prioritise research focused on improving the quality of life for people with severely life limiting conditions Principle 12: Consider areas that will impact on quality of life	➢ Is chronic fatigue just your brain saying, 'give me time to recover'? ➢ Is chronic fatigue caused by bad aftercare immediately after a stroke? ➢ Why do some people get chronic fatigue after a stroke and others don't? ➢ Would temporary chronic fatigue have an effect on your overall health over time? ➢ Can you prevent strokes from happening? ➢ Does a part of your brain die when you have a stroke? ➢ What happens in your brain when you develop the foreign accent syndrome?

While it is difficult to confidently single out why certain case studies fared well in certain groups and locations, and less well in others, it is important to note that discussions around those eight topics clearly show participants' interest in NMH **fundamental research questions** increased throughout the dialogue. While most were **initially drawn towards applied research,** focused on finding new treatments for diseases and disorders of the nervous system at the evening events, their **interest in fundamental research** did not only gradually deepen, but actually **ended up dominating** throughout the discussion of the case studies with the experts.

Broadening participants' thinking on the research areas

At the post-research summit, participants were asked to further explore three of the research areas discussed at the Saturday workshops. Those case studies included:

- The two case studies that ranked the highest for participants in terms of interest and importance: '*How does the brain develop?*' and '*How do emotions affect the immune system?*'

- The case study '*Which part of the brain controls sleep?*' - it is important to note that although this case study did not rank especially high at the Saturday workshops (i.e. it was the fourth most popular case study), sleep was a popular and recurring theme throughout the dialogue.

Participants were asked not only to re-discuss those topics but also to **broaden their thinking** and come up with **new research questions** around each theme. Participants' thoughts and questions were also captured by illustrators on the day.

How does the brain develop?

This case study ranked the highest across all groups. Similarly to the Saturday workshops, many discussions at the summit revolved around the **nature versus nurture debate** which participants were especially keen to talk about. In discussing it, they raised a number of questions around:

- what is **within our control**, and whether there are underlying traits or conditions (such as psychopathy) that are part of our genetics but then triggered by our environment.

"If we can find definitive answers about things that are nurture rather than nature, it's worthwhile investing money in these things. It seems more hypothetical than very scientific, but the more we answer that question, the more we can say, 'It is very much connected to wellbeing." (Male, London summit)

- **the differences between genders**, and whether those were attributable to genetics or learned culture, and the impact of certain events in **women's lives** (such as pregnancy or menopause) on brain development:

"You've got nature versus nurture already, but are there differences in terms of does the brain change when the woman's pregnant or going through menopause?" (Female, London summit)

- whether **sexuality** was linked to certain genes in the brain or was influenced instead by external factors.

- how the **brain develops through time**- especially in the womb and what this could mean for the prevention of certain conditions.

"In the womb, what parts of the brain develop first and does that change with each individual person?" (Male, London summit)

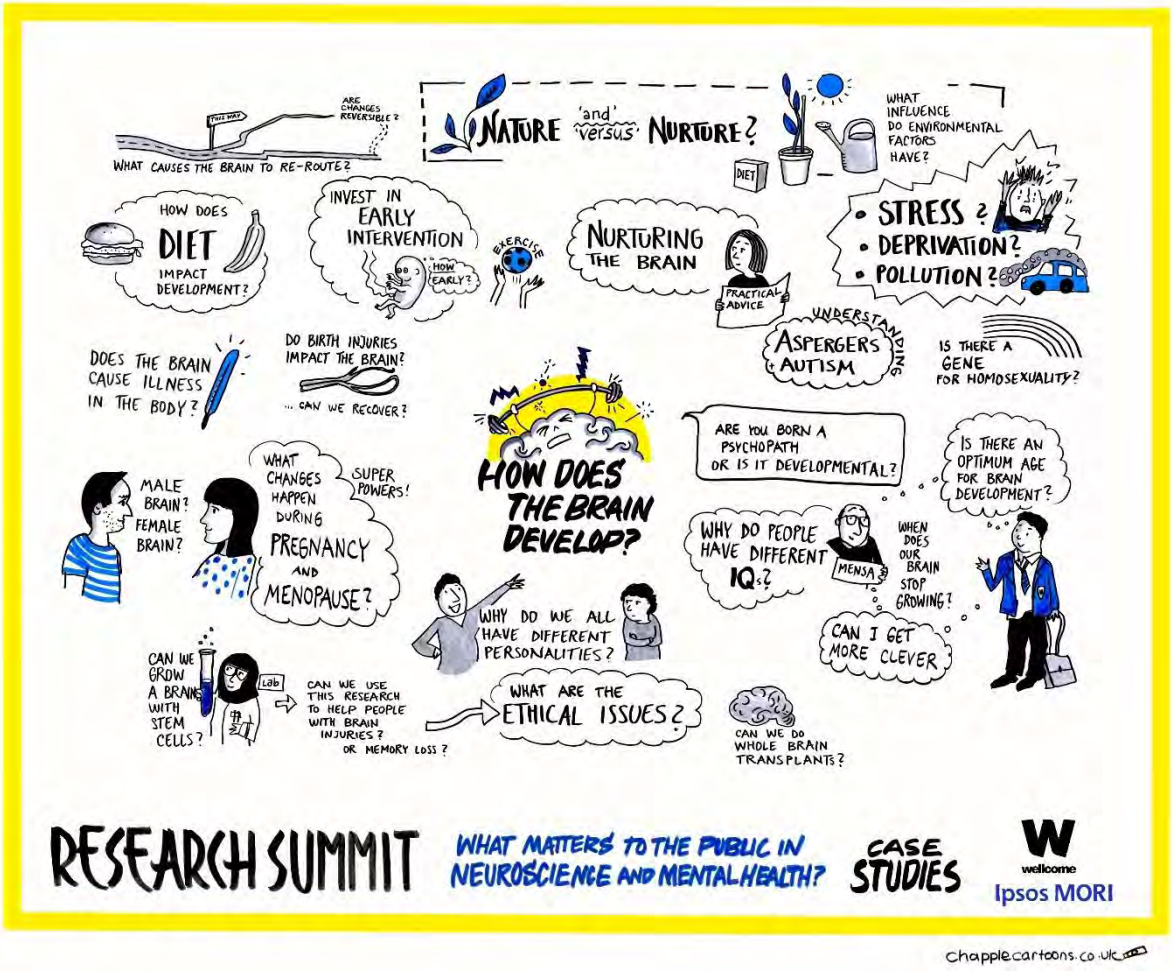
- how **lifestyle,** including levels of stress or diet, can affect brain development. Considering diet, one participant wondered if processed and unhealthy foods and the additives they contain could have an impact on the brain and what the potential implications are for health inequalities.

- how a **negative environment, and stressful events** (including a traumatic birth) could negatively impact on brain health:

"If you were born at my age, you don't have to worry as much, whereas if you were born during World War One or Two, you have those worries and all the blackouts, which would change your brain and the way you think." (Female, London summit)

Thinking ahead about potential implications for this area of research, participants **foresaw a range of potential benefits** such as being able to silence genes or alter brain cells, or even create new ones 'from scratch' to stop or reverse certain illnesses from occurring. Saying that, participants questioned whether such research would be **ethical.**

Figure 1.5: Illustration of how the brain develops discussion



How do emotions affect the immune system?

This case study ranked high among participants because of its potential wide societal implications in terms of the numbers of people it could benefit and how it could help the NHS save money.

Participants were naturally drawn to discuss how emotions did not only affect one's mental health, but also physical health. They also wondered how these could affect overall brain health and whether illnesses could directly impact brain development and how.

"How the brain is processing – is it different before the illness versus after it? What happens in the middle of that? At the end, you're physically recovered, but is your brain the same?" (Female, London summit)

Similarly to when discussing brain development, participants questioned the role the environment played in one's ability to process emotions. Rather than talking about the immune system itself, participants often broadened their thinking and discussed health in wider terms of both physical and mental health. In doing so, participants brought a range of environmental factors such as:

- The country people live in and cultural differences

"Is there a cultural difference to emotions? Maybe in Africa, people might not feel as bad as people in Europe feel, for example." (Male, London summit)

- Lifestyle factors such as diet, lack of sleep, stress and grief

"I went through an extremely stressful period in my life. I developed shingles. That was an immune system thing (…) It really dragged me down. How do you stop that, something having such an impact on your health?" (Female, London summit)

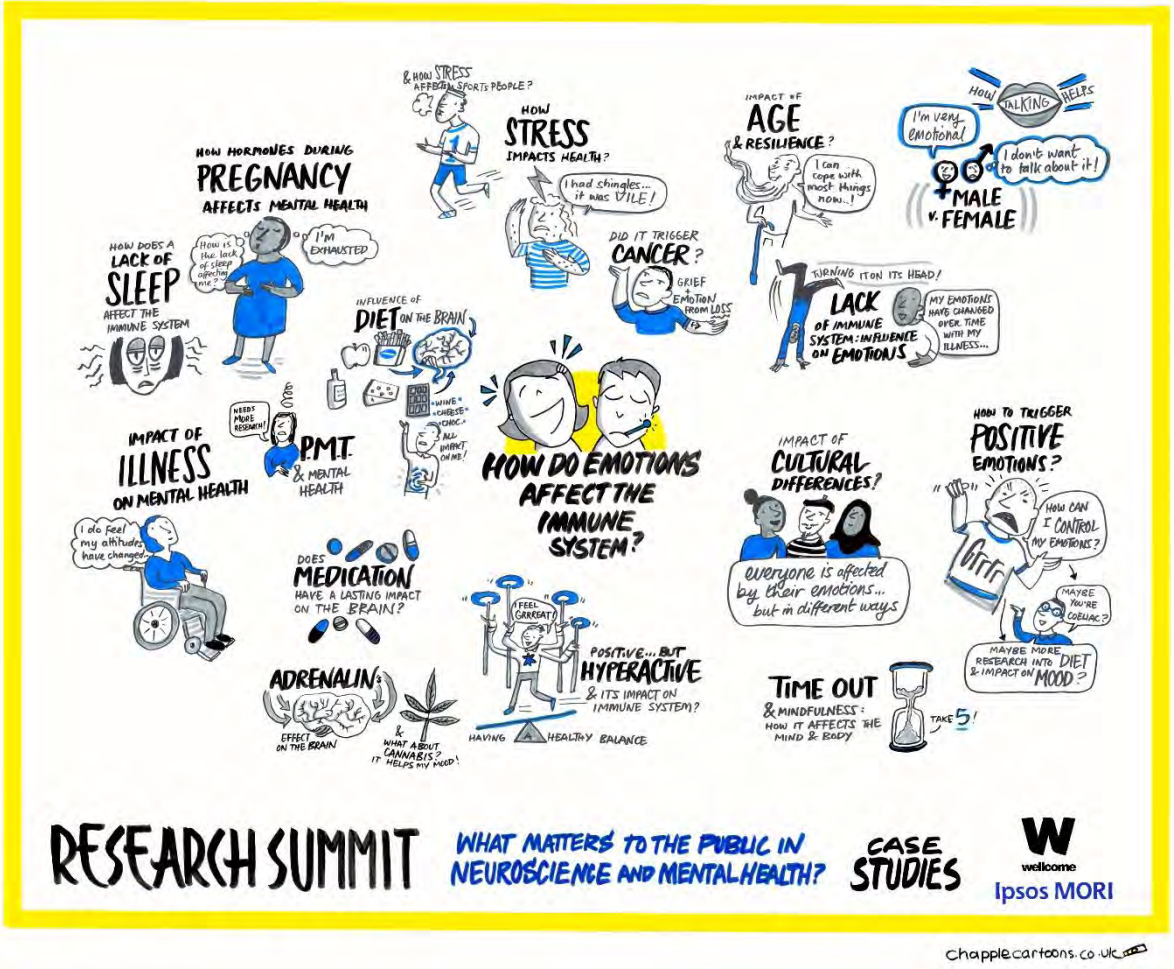
Again, similar to when discussing brain development, participants were keen to talk about the role of hormones, and more specifically how hormonal effects (pregnancy/menopause/puberty) could affect the brain and our ability to deal with emotions.

[Talking about a family member] *"She's going through some mental health issues at the moment. We're trying to track her cycle to see if it's a hormonal thing."* (Female, London summit)

When participants narrowed down their discussions around debating the link between emotions and the immune systems more particularly, the following questions were raised:

- Which comes first: the negative emotions and poor mental health leading to illness or the opposite?
- How are emotions and brain development linked? And why may some people be predisposed to be more positive or negative in their outlook of life?
- How can non-medication interventions such as mindfulness and cannabis (over selective serotonin reuptake inhibitors for instance) help with improving one's mental but also physical health? There was a general agreement that 'natural remedies' would be better for you over synthetic ones, although not everybody agreed.

Figure 1.6: Illustration of how emotions affect the immune system discussion



What part of the brain controls sleep?

Sleep generated much interest across all groups throughout the dialogue. At the summit, when asked to delve deeper, and to reflect on what interested them about sleep, the following themes and questions emerged:

- What are the long-term effects of sleep deprivation? (and conversely, but to a lesser extent), what is the impact of oversleeping?
- Why do sleep patterns evolve with age?
- Why do some people need more or less sleep than others?
- How can we improve our understanding around optimal individual sleeping patterns in order to maximise brain health?
- Why do you need more sleep when you are ill? And what is the effect of sleep on your immune system?
- How certain conditions such as autism, dementia or schizophrenia can affect your sleep, and how can this impact on brain health?
- How to get the benefits from sleep with less sleep, maybe through meditation and a substitute activity?

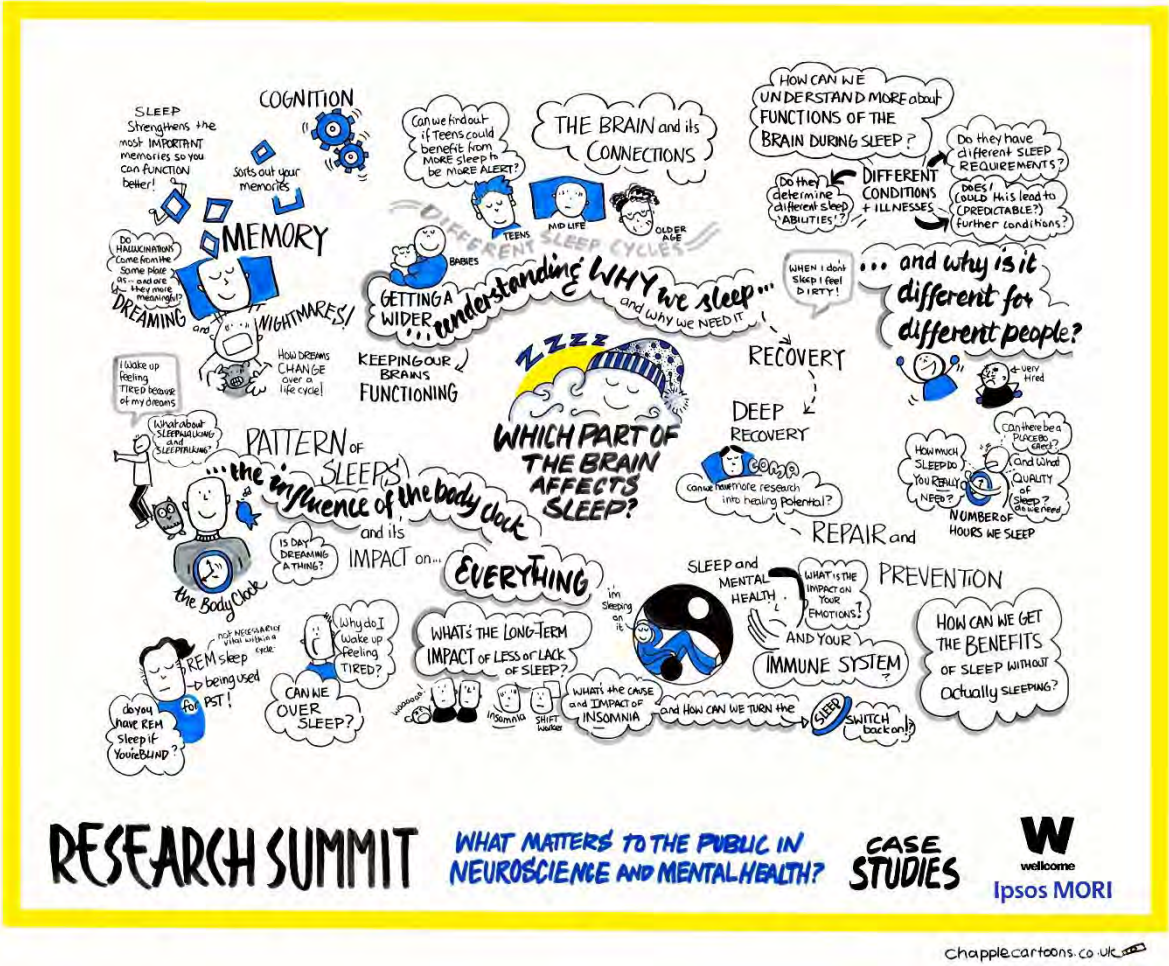
- Is our perceived need for sleep equal to having a good sleep? Is there a 'placebo' effect when it comes to sleep?
- What is the meaning of dreams and nightmares, and how does this impact on our mental health?

Other topics raised included sleep walking and paralysis, and the link again between sleep and healing - including sleep induced coma.

Overall, there was a widespread acknowledgement that understanding more about sleep was critical and could have far-reaching implications, and that Wellcome should prioritised this area of NMH research.

"Everybody says that we are all different people so maybe we can do more research into sleep habits by looking at how different people sleep." (Male, London summit)

Figure 1.7: Illustration of which part of the brain affects sleep discussion



Chapter summary

- While participants tended to view science and research as **abstract and distance**, they also considered it highly **beneficial**. On the whole, they found the areas covered by NMH research of particular interest and importance. They also demonstrated an eagerness to improve their understanding of the brain, even though it was initially limited.

- Initially, participants tended to show an interest in conditions they had a **direct or indirect experience** with, and more applied research- with most participants particularly interested in finding **new treatments** for diseases and disorders of the nervous system. However, as the dialogue progressed and participants increased their understanding of NMH, **their interest widened** and they became increasingly keen to discuss **big, fundamental questions (notably the nature versus nurture debate).**

- The main principles participants used to prioritise the research were:

1. Consider the potential impact to society- in terms of cost saving to the NHS and increasing our understanding;
2. Focus on prevention rather than treatment or a cure; and
3. Prioritise research focused on improving the quality of life for people with severely life limiting conditions.

- Overall, when participants were able to think in **broader terms** and conceive the **wider impact** of a case study, it tended to rank well in terms of **interest and importance**. They were often able to do so when discussing **fundamental research topics.** They felt such topics needed prioritising because, although long-term, their benefits could also be huge.

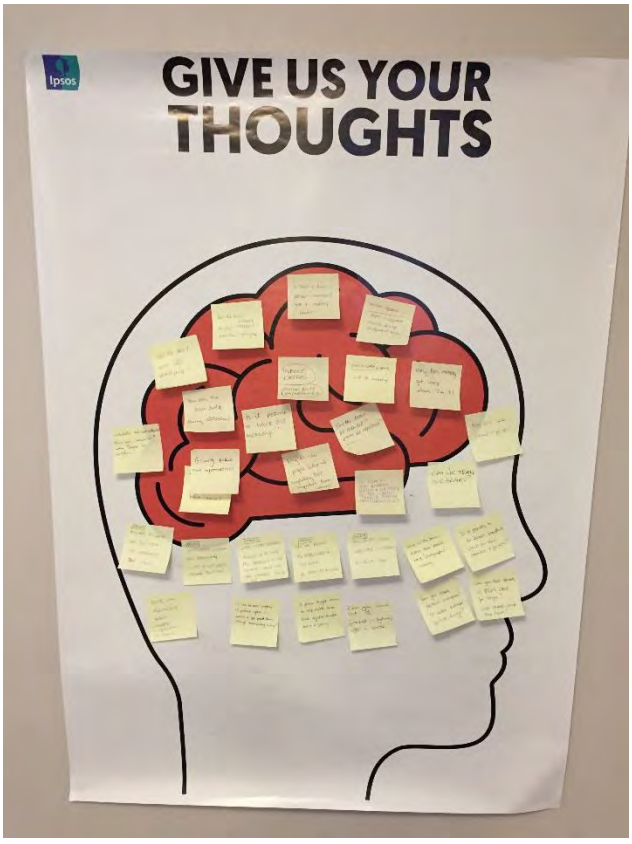
- Case studies which concerned diseases or illnesses strongly impacting on the quality of life of individuals tended to be considered as both very interesting and important even though they affect only relatively small numbers of people. Yet when it came to funding prioritisation, they ranked less well as participants **struggled to see their wider applicability**.

Participant led ideas and questions

A core pillar of Wellcome's Public Engagement strategy is to empower people, helping them to access, use and respond to health research and innovation. Therefore, Wellcome was keen for as much of the dialogue to be participant led as possible, with the generation of ideas and questions coming from participants based on what *they* were interested in and saw to be important. There were various sessions that needed to be led by the facilitators, to provide information to inform and stimulate discussion (for example the case studies), and also to encourage participants to think about a broad range of topics (i.e. both fundamental and applied research questions). However, all sessions and exercises were designed to open participants up to offering their ideas. There were also sessions and specific activities which stand out as being almost entirely participant led. This section reports specifically on these.

Brain diagram post-it note exercise

During both the evening and Saturday workshops, participants were encouraged to jot down any questions or ideas they had which related to neuroscience and mental health research, and to stick these (using post-it notes) onto a large diagram of the brain. Facilitators also added to this with questions that participants were asking, or areas that participants were volunteering as interesting and/or important to look into further.



While there was a wide range of questions and ideas offered by participants across the three locations, and during both the evening and Saturday sessions, a number of reoccurring themes emerged.

- Brain development: For example, whether you can train the brain; Whether the brain develops during adolescence; Why are some people left-handed; Why do some people develop mental illnesses when their siblings don't; Whether phobias are a learned behaviour; whether mental illness is genetic or environmental.

- Personality and mood: For example, how are personalities formed; How does your brain affect your mood; Why do some people abuse animals; Does personality drive behaviour; How can neurological conditions effect/change personality; Why do certain noises irritate us; Why do we make decisions we make.

- Effects of lifestyle on the brain: For example, whether eating certain foods or leading a certain lifestyle affects the brain in later life; Whether phones / pylons cause brain cancer; What makes people become addicted to drugs, cigarettes and alcohol; Is serotonin released when we exercise? What effect would having the TV on all night have.

- Detection of brain disorders and mental health conditions: For example, whether a healthy brain actually looks different to the brain of someone with mental health problems; Whether an unhealthy brain can be identified, using an MRI scan; How is language affected by as stroke; Does the brain have an infinite capacity; How do you identify brain issues; Does a normal brain show the same as an ill one.

- Brain and body interactions (e.g. hormones): For example, if positive thoughts/emotions can shrink tumours, could negative thoughts lead to it growing; Does the brain control the immune system; Do continuous negative thoughts, e.g. depression, physically alter the brain or just affect synaptic pathways – hormone imbalance; Why does anxiety get worse when we're ill; Is there a link between menstrual cycle and mental health; Are pain and hunger controlled by the same region of the brain – and is that why we get 'hangry';

- Brain recovery and regeneration: For example, can the brain be mended; Can parts of the brain be replaced; Can we prevent the deterioration of the brain, e.g. after an accident Can you live with half a brain; Is it possible to do brain transplants – which can keep memories and functions; Can brain cells regenerate after trauma; Can you come out of locked in syndrome after a stroke; If your brain dies, are you dead.

- Alternative therapies: For example, how can cannabis oil help; How does hypnosis work.

- Sleep: For example, is your brain working when you are asleep; Do we need to dream; What is the impact of disturbed sleep (in children); Do humans dreams and are dreams important; How do we sleep; Why can dreams be so random; Why do we sleep; Why do some people remember dreams and some don't;

- Memory: For example, whether research could allow us to access memories that our brain has blocked out; What in the brain means some people have 'photographic' memory; Can you delete certain memories or better remember positive ones; Is it possible to block out memory; Why does an event make the brain stop memoires of that event; How do we store memories; Why do we memorise traumatic memories more than good memories.

- Brain illness and mental health conditions: For example, what is the difference between Alzheimer's and Dementia; Research into headaches; What can be done long-term and short-term for OCD; What causes OCD; Why is Alzheimer's growing as a disease; Is mitochondrial DNA passed through the female DNA; Are problems with hearing and sight mainly issues with the brain or the sensory organs; What makes you a

psychopath, is it a chemical imbalance; Is Tourette's syndrome an overlooked problem in medical research.

- Neuroscience and mental health research processes: For example, is this study about mental health or brain illness and injury; Is there a bias between young and older people in the views on funding research and neuroscience; Who in the professional world holds the most knowledges about the brain; How many people does Wellcome research, per project; Why is research slow; What are the ways to measure electrical impulses in the body.

- Miscellaneous: For example, Is the brain an organ; How adaptable is the brain when it comes to situations; Why are some people better at regulating their temperature than others.

Exploring participant's questions in more depth

We picked 18 questions participants had generated themselves via the brain diagram (mentioned above) and asked them to choose the questions/research areas that interested them most and were linked to their top three principles:

- to the prevention of onset of problems with the brain, self-help and self-care.
- understanding why people are different, inherent vs learned behaviour.
- the potential of alternative therapies to be used instead of drugs, as well as cost savings to the NHS.

How does your lifestyle (diet, exercise, drugs) affect the brain?

Participants were interested in this question for two related reasons. First, because of the desire to want to find out about self-help and self-care strategies in order to prevent the onset of problems. This relates to Principle 2, around prevention, but also Principle 8 (self-help and self-care).

Second, it is important for young people to understand the effects of the decisions that they make so that they realise the impact of drugs and alcohol on the brain, as well as on the body. Participants who chose to speak about this topic also talked about exercise and how this can release endorphins.

The questions participants had included:

- How can we help ourselves?
- What can those who are not able to exercise do instead to help themselves?
- What impact does exercise have on you / What are the consequences if you don't exercise?

- Does how you live impact on your brain? For example, poverty, your education, surroundings, relationships and life choices.
- How do Class A drugs impact on the brain?
- How do medications impact on the brain? (side effects).

Why do we make the decisions we make?

This question interested people from the perspective of **inherent/learned differences** between individuals, for example in personalities as well as reactions to situations. Participants were keen to know more about research that could establish how to help people with addictions or those making the wrong choices, for example by producing findings that would nudge people into **changing their behaviour** (alcohol, as an example).

The questions generated here included:

- What makes you the person you are?
- Why do you like the things you like?
- Why does your brain like things and how do preferences come about?
- Why do people make decisions that can negatively impact themselves?
- Why do some people like an element of risk and not others?
- What is the role of impulse?

Can cannabis be used to treat certain conditions?

This question was the one question that interested the most participants. Those who were able to discuss it in more detail reported being appealed by the potential of cannabis as an **alternative therapy or treatment**. This relates to Principle 9. There were participants in the group who discussed this question, who had direct experience of how cannabis had improved the situation for people they knew where other medication hadn't been successful, for example, to treat seizures. Other participants cited examples they had heard of in the public eye of the **health benefits of cannabis**. For example, American footballers who had used cannabis for their sports injuries instead of prescription drugs – which incidentally had had negative side effects such as increased anger. CBD oil was also noted for helping people. Participants were attracted to the idea of researching cannabis, from the perspective of the potential of cost savings to the NHS too (Principle 4).

The kinds of questions that participants generated here were as follows:

- What does each of the 52 different components found in cannabis do, and how can they help people individually?
- Could cannabis have benefits during pregnancy or be used as pain relief during childbirth?
- How does smoking cannabis during pregnancy affect the baby?
- Can cannabis be used to treat arthritis?

Current and future challenges for our health and wellbeing

During the Saturday workshop, participants were asked to think about the **current societal and health challenges** that we are facing now, and also in the future. The table below shows the challenges

identified by participants in the dialogue and the research questions they generated which could address these.

Table 1.5: Future challenges and potential research

Current and future challenges	How research might be used to address these
Mental fatigue due to the demands of work	➢ Would a 4-day week be beneficial to our health? ➢ What are the effects of caffeine on our brain? ➢ What can we do to reduce stress?
Population and demographic changes, increase in mental health problems and age-related diseases and obesity rates rising	➢ Why do some families tend to live longer than others? ➢ What are the effects of obesity on the brain? ➢ What can we do to reduce the chances of having a stroke?
Technological advancements	➢ What will be the impact of automation (loss of jobs) on our wellbeing? ➢ What happens to our brains when we are not exercising them as much? ➢ How will our brains keep up with the pace of learning and adapting to new technologies? ➢ Is brain cancer connected to phone use?
The rise of social media, a reduction in privacy and a loss of connectedness	➢ What is the impact on the brain of spending more time on social media? ➢ What is the link between social media consumption and stress? ➢ How are sites like Instagram (showing photos of models) affecting our mental health? ➢ What are phones doing to the brains of children?
Climate change and the effects of pollution and deforestation on our health	➢ How does the brain react to temperature increase? ➢ What will be the impact on our brains of consuming 'polluted' food? ➢ How resilient is the brain to different environmental conditions, like pollution?
Financial, economic problems such as poverty and food shortages	➢ What is the impact of worrying about money on our brain? ➢ Will having less nutritious food, due to poverty, affect our brain?

Chapter summary

- Through the dialogue process, participants were encouraged to generate **their own ideas and questions** which were captured and explored further.
- While there were a wide range of ideas and questions generated throughout the participant led sessions, a number of clear themes emerged around what people were interested in. This included; Brain development; Personality and mood; Effects of lifestyle on the brain; Detection of brain disorders and mental health conditions; Brain and body interactions (e.g. hormones); Brain recovery and regeneration; Alternative therapies; Sleep; Memory; Brain illness and mental health conditions; and a number of questions specific to neuroscience and mental health research processes.
- These participant generated questions and ideas were taken further at the summit, whereby participants discussed three popular research areas and generated further questions:

1. **How does your lifestyle (diet, exercise, drugs) affect the brain** – participants were interested in the self-help and self-care aspects of this area, as well as being able to prevent the onset of problems. They were also keen for research to be able to inform those who drink alcohol and take drugs about the impact of their decisions on the brain.
2. **Why do we make the decisions we make? –** participants were interested in this area from the perspective of inherent vs learned behaviours. The self-help element was discussed again in relation to how research could lead to discovered which might help to those with addictions.
3. **Can cannabis be used to treat certain conditions? –** this area was of common interest to participants because of the potential of cannabis as an alternative therapy or treatment to drugs. Participants were also attracted to the idea of researching cannabis and its properties from the perspective of the potential cost savings to the NHS too.

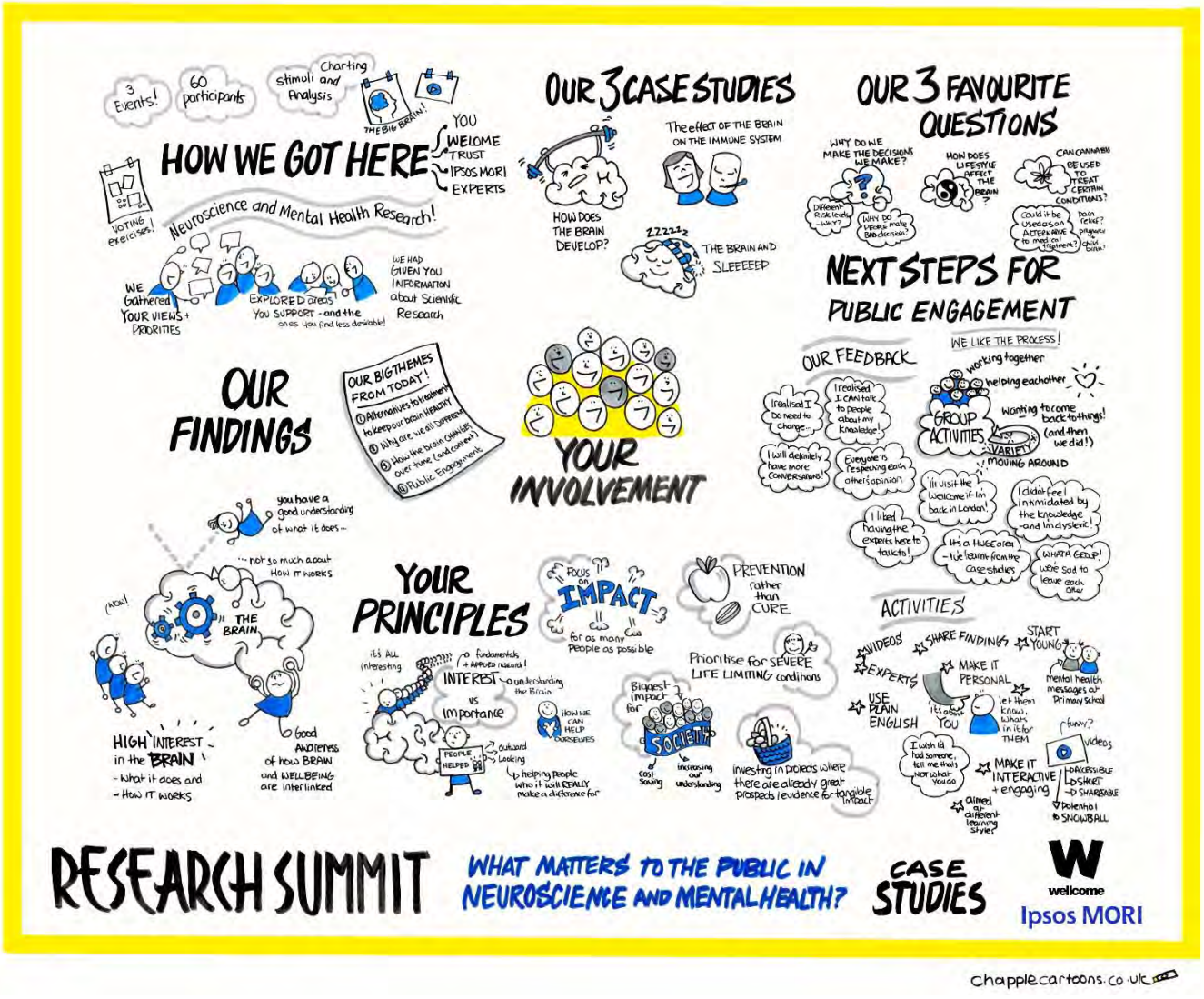
- Finally, in a different participant led session, dialogue participants discussed a number of current societal and health challenges that we are facing now and also in the future and came up with a number of areas that research could be used to address these. For example, in relation to climate change, researching how the brain reacts to increased temperatures. And in response to technological advancements, looking into whether brain cancer is connected to phone use.

Engaging the general public in a NMH dialogue

Towards the end of the research summit, and as part of the final wrap-up table exercise, participants were asked to reflect on the entire dialogue, and on public engagement more widely. To complement this, participants' thoughts on the summit and on their overall involvement were also captured by one of the illustrators on the day.

This section reports on participant's reflections of their involvement, and also on their views and opinions towards engaging the public more widely in science and scientific research.

Figure 1.8: Concluding illustration from the Summit



Reflection on techniques to engage the public in a meaningful deliberative dialogue

It was clear that involvement in the dialogue had exceeded the expectations of participants in the room. Some, for example, commented that they had expected to be overwhelmed and even "*belittled*" by the science. This, however, had not been the case. Others said that they had not expected to have been as interested as they had become.

"I don't feel as if I'm blinded with science. I didn't feel intimidated, when normally I would. But I haven't this time." (Male, London summit).

"I've enjoyed it so far. I've gotten more out of it than I thought." (Female, London summit).

"Why did I come? For the money. After the first one I was really looking forward to coming to this one, because I do enjoy talking about it and listening to other people's ideas." (Male, London summit).

Recognising that NMH is an extremely complex and vast topic, the dialogue was praised for being conducted in a way that was understandable. It was clear too that participants found the dialogue interesting, engaging and enjoyable.

The dialogue presented people with a new opportunity to think about NMH, and in particular, the brain. Some participants recognised how society is becoming more open to talking about these issues than ever before, and there were some suggestions that being involved had made people think about their own health, body and health-related decisions.

"It made me think I do need to change how I am, to focus on sleep, and have a better outlook on life" (Male, London summit).

It was common for participants to reflect on how surprised they were by how engaged and talkative people had been, especially coming back to it at the second event and *still* having lots to talk about and contributions to make. Being able to listen to other people's opinions was described as 'eye-opening'. People talked about how the generation of ideas from those involved had made everyone feel like equals. Similarly, people noted how respectful people had been of each other's opinions.

"Everybody is different. Nobody's the same. No one's arguing that anyone is wrong. Everyone is just accepting everyone's opinions. Last time, we had to decide where the money should go, because everyone is so different. But in the end, we all came together." (Male, London summit).

"No one's laughing at what I say, or what anyone says." (Male, London summit).

The interesting topic, as well the way the dialogue was conducted with a variety of activities which made it engaging and interesting, made people speak highly of their involvement and the experience.

[Responding to a question about whether the topic has been interesting of the way that they have been engaged] "*I think both. There are so many different elements. Like the quiz we did, I had to go ask my*

friends these questions, because I found them fascinating, like, 'What is the brain made of?' I've just found the whole experience very good, the speakers have been excellent, they've helped my attention."

(Female, London summit).

Selection of quotes from the Evaluation questionnaires

"Really enjoyed the sessions, was looking forward to the second one. Very informative and interesting. Fun way to learn and share opinions."

"Thank you for the great experiences and for helping me heighten my awareness and understanding."

"I would also like to thank you and Ipsos MORI for giving me a wonderful experience. Everyone was really nice and always smiled, it was a fantastic environment to be in."

"Thank you so much for the opportunity to take part in this research. I found the subject to be both fascinating and inspiring - it has definitely altered my views on the brain and mental health. Your team worked very hard to make the sessions both welcoming and interesting."

Feedback on specific aspects of the dialogue and the techniques used

There were particular aspects of the dialogue that participants made specific comments about:

- The pace: It was felt that the length of the sessions (evening and Saturday workshop) had been appropriate and no comments were made to suggest that they were too long. The summit (3 hours long), however, felt a little rushed and some would have liked longer on the topics, instead of being moved swiftly on.
- Experts: Dialogue with the experts was viewed as engaging, in particular where experts interjected and asked questions and probes to expand on people's initial ideas. It was felt that this aided participants, both in terms of their thinking and their understanding.
- The summit: Unlike with the previous (evening and Saturday) sessions, where people came to them uninformed, participants talked about how they came to the summit having had time to reflect, which was appreciated. The summit was also considered a necessary closing event, to bring everything together.

There were also certain techniques that participants reflected on:

- Actors: On the positive, participants appreciated the actors and commented on how fascinating this had been, with some of the improvisational sketches being described as powerful, and also how they had lightened the mood.
- Illustrators: Participants were comfortable to have the illustrators present at the final summit, to document everything. This was compared to earlier techniques which were instead used to stimulate thinking and discussion (the actors for example).
- The carousel activity: The activities which involved moving around, for example the carousel activity at the summit, was liked for how it allowed for a good pace and meant that participants didn't have to spend too

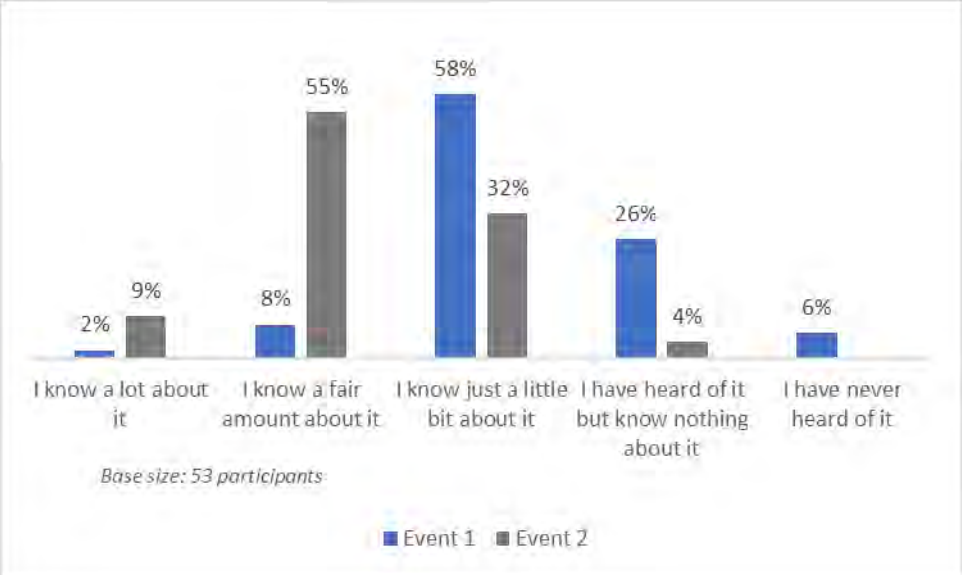
long talking about one area. On the flip side, there was also some reflection that people would have liked to have spoken about things in a little more detail (as mentioned above in relation to the pace of the summit).

Finally, considering the entire journey, and reflecting on this during the summit, there was a feeling that people were thinking very differently to how they had done at the start of the dialogue. Some participants cautioned that people will give very different contributions once they are informed, compared to how they might respond coming to a topic like this fresh, and without the time to reflect.

"I think the journey has completely informed my decision-making. It's made me think about it fundamentally much more. The way I think about it now is completely different to how I thought about it then". (Female, London summit).

As can be seen in the chart below, participants' responses to a 'knowledge of neuroscience and mental health research' question shifted quite dramatically over the course of the dialogue. At the start of the dialogue (beginning of the evening evening), 8% of participants who responded reported that they knew a '*fair amount about it*'. This increased to 55% at the end of the 2nd event (Saturday workshop). Similarly, 58% of participants reported that they knew *'just a little bit about it*'' at the start of the dialogue, and by the end this had decreased to 32%.

Table 1.6: Tracking questionnaire responses to 'How much do you feel you know about neuroscience and mental health research?'



Participants were asked at which point they felt as though they became informed, and where all of the information they had received had clicked into place (i.e. the 'lightbulb moment'). There were occasional mentions of the case studies, and how they had bought the science to life and made it feel real, as well as moving the session on from the overall to specific examples.

However, for most it wasn't necessarily one technique or moment in time that people recalled. Instead, participants referenced the range of stimulating techniques and the journey that they had been on. The journey had been about learning and the sharing of ideas. Some participants talked about how they felt they now had a better understanding of neuroscience and how vast an area it is. Others spoke of how they would feel more confident having conversations about the topics. Involvement in the dialogue had stimulated some to want to find out more. One Female participant, who was incidentally in her late 50s, spoke of how she found the topic so interesting that she wanted to find out more, and was considering going back to university to study psychology.

"Yes, I feel more confident about having conversations about this topic". (Male, London summit).

"I had a chat with a couple of my friends who had issues with mental health. Following the session, I had last time, my ability to absorb the information was different. I was able to get perspective". (Male, Canterbury, Saturday workshop).

In the tracking questionnaire, participants were asked how confident they felt talking about science topics, how likely they were to seek out information about neuroscience and mental health, and also to discuss topics relating to neuroscience and mental health to others. At the start of the dialogue (beginning of the evening workshop), 40% of participants who answered reported that they were '*fairly confident*' talking about science topics, which rose to 72% by the end of the dialogue (end of the Saturday workshop). Of those who answered about likelihood to seek out information about neuroscience and mental health, 15% of participants reported that they were '*very likely*' to do this, which rose to 34% at the end of the dialogue (end of the Saturday workshop). Similarly, 19% of participants who answered at the start of the dialogue reported that they were '*very likely*' to discuss topics relating to neuroscience and mental health to others, which rose to 34% by the end of the dialogue.

Table 1.7: Tracking questionnaire responses to 'How confident do you feel talking about science topics?'

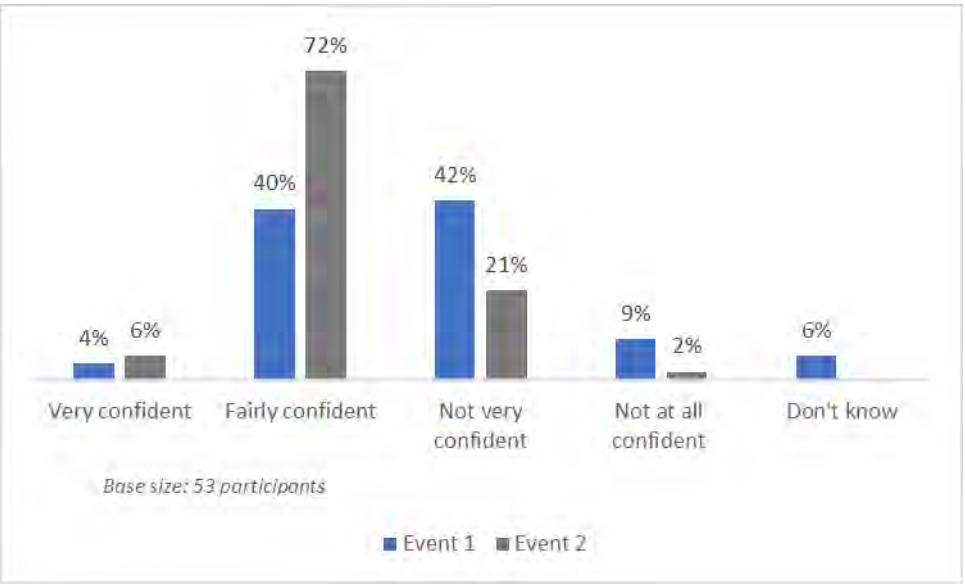


Table 1.8: Tracking questionnaire responses to 'How likely are you to seek out information about neuroscience and mental health?'

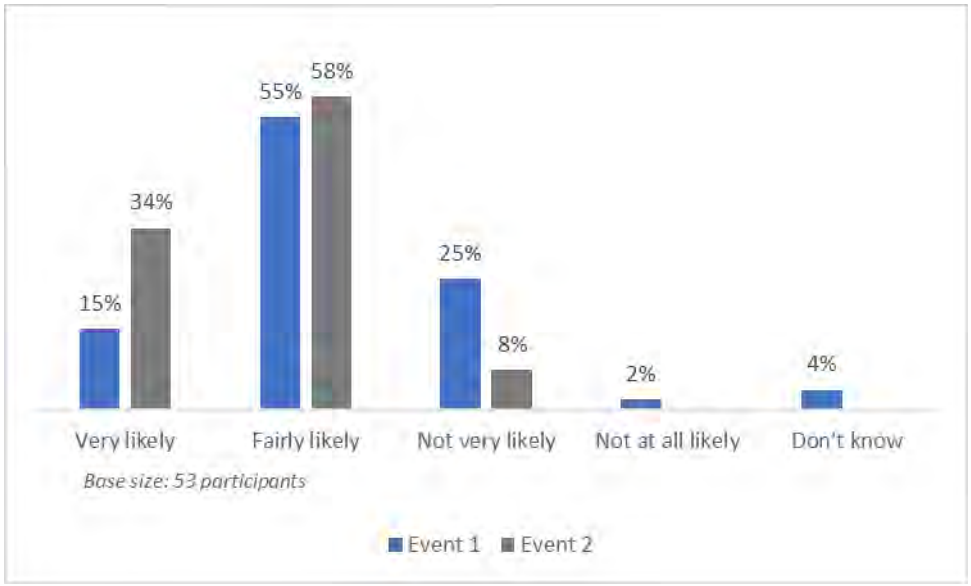
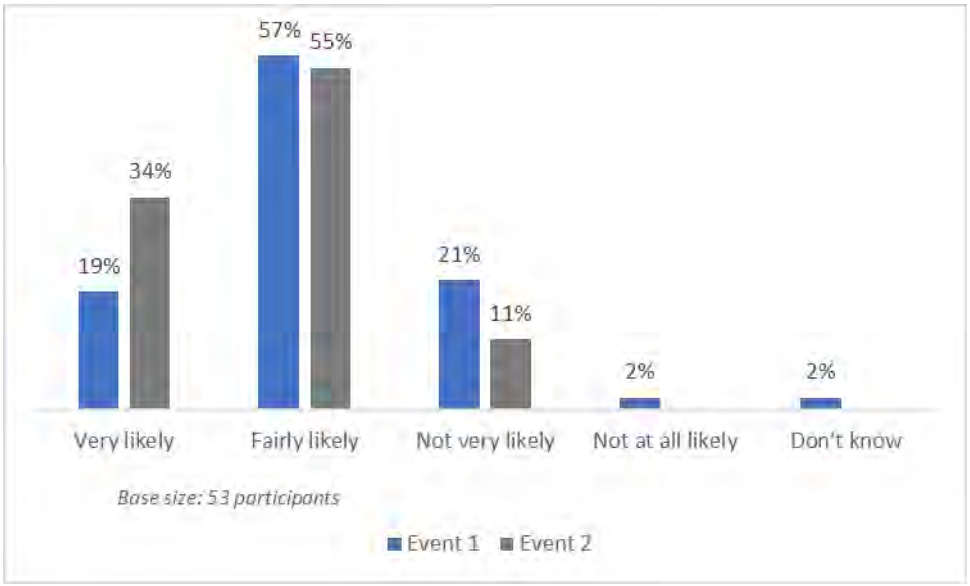


Table 1.9: Tracking questionnaire responses to 'How likely are you to discuss topics relating to neuroscience and mental health to others?'



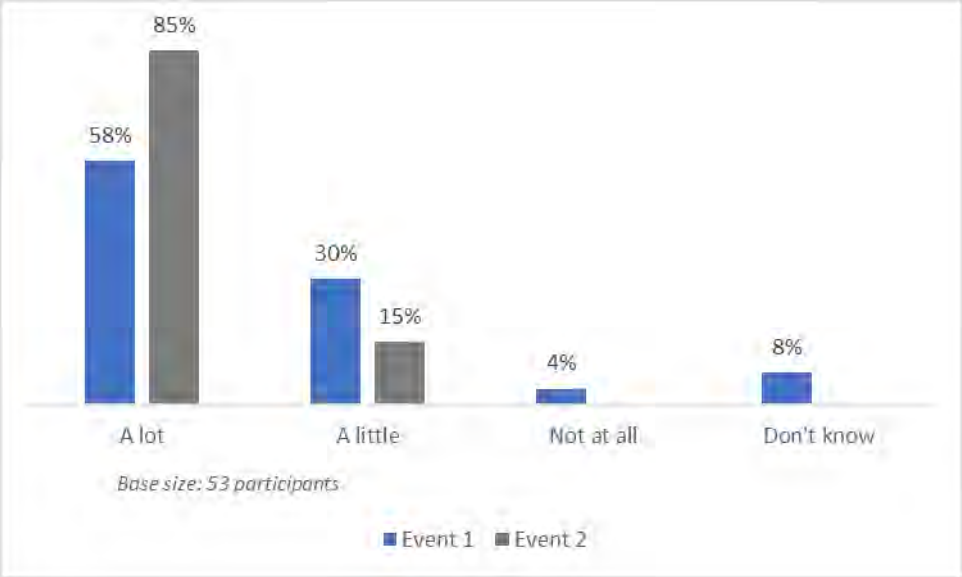
Identification of opportunities for future engagement

There was a general agreement that the public should be involved in decisions about science and research. There was also an appreciation for organisations like Wellcome who are engaging with the public to inform decision making.

"It's good. The government isn't just dictating where the money goes. They're [Wellcome] *finding out what people want".* (Female, London summit).

In the tracking questionnaire, at the start of the dialogue 58% of participants who answered reported that the public should be engaged in setting the direction of science and health research '*a lot*'', and this rose to 85% of participants by the end of the dialogue. On the flip side, by the end of the dialogue no-one reported *'not at all'* when asked about the extent the public should be engaged.

Table 1.10: Tracking questionnaire responses to 'To what extent, if at all, do you think the public should be engaged in setting the direction of science and health research?'



However, participants in one group raised the issue for Wellcome in how it effectively reaches all ages and types of people. Recognising that it is easier to access children and young people, in schools and universities, it becomes more difficult to engage people after this point and requires different approaches.

The ingredients for successful public engagement

Regardless of who is being engaged about science and scientific research, participants were clear that the techniques need to be interactive and fun, ideally identifying the aspects of the research design and/or findings which will benefit individuals personally. Engagement techniques should be designed to speak to different ages, for example, by using social media and Apps for young people, and workshops and science fairs for

older people. Short films and documentaries could work as a target for all ages because of their reach, for example, they could be shown in school, as well as aired on national television.

We asked participants to design their own engagement approach, thinking about who they would engage with and how, and choosing a topic of their choice. Participants worked in small groups during this exercise. Some groups came up with ideas for how to engage the public in forming research questions (as shown in example 1 below) and were keen for this to happen for reasons mentioned already above. However, it was more common for participants (in their group work), to focus their engagement plans on the dissemination of research findings (as shown in examples 2 and 3 below).

The examples below show some of the engagement strategies that the mini groups came up with in this final session.

Figure 1.9: Example 1: Public engagement for research focussed around how technology affects our brain

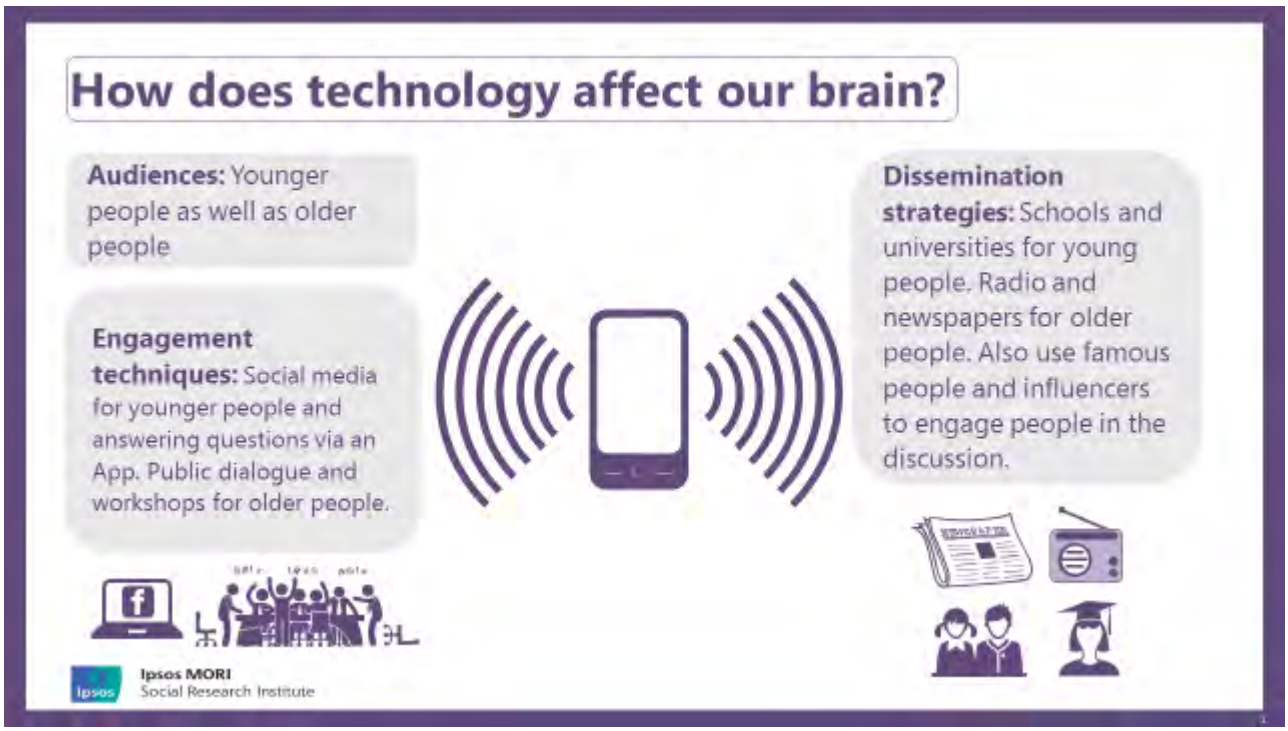
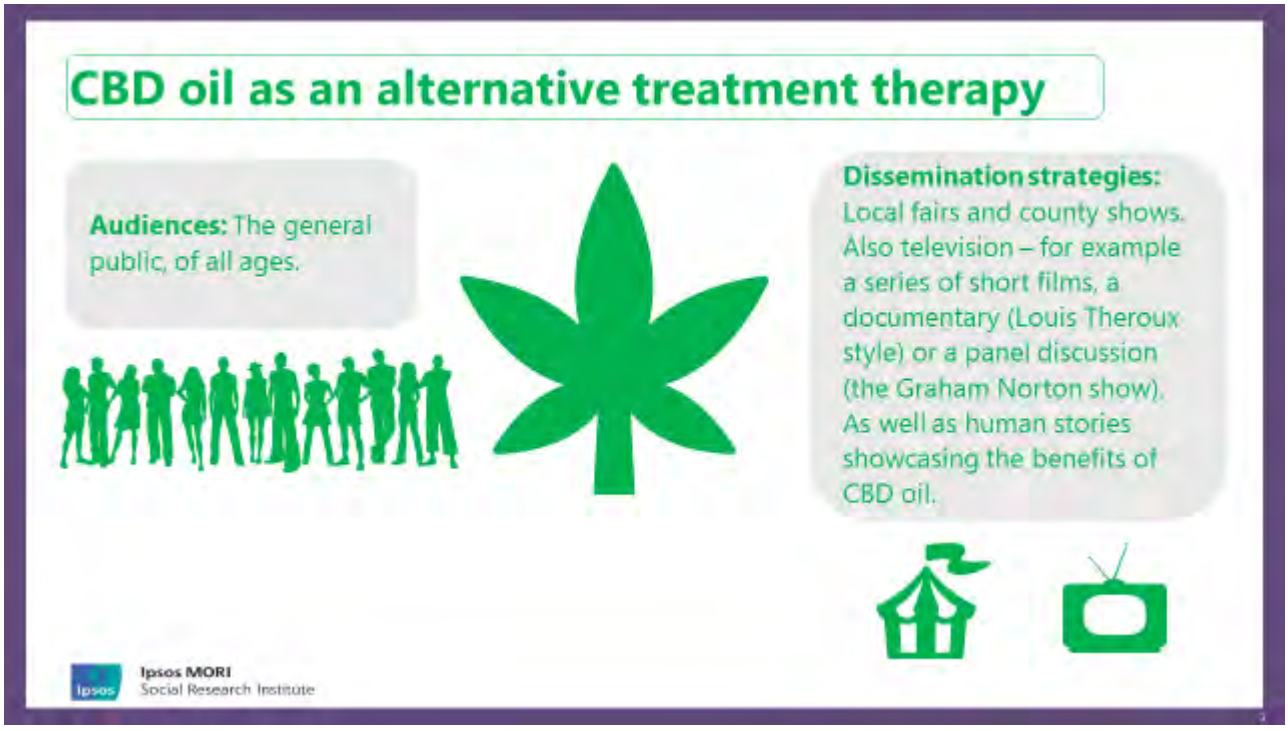


Figure 1.10: Example 2: Public engagement for research showing the benefits of mindfulness

Figure 1.11: Example 3: Public engagement for researching suggesting CBD oil as alternative treatment therapies



Chapter summary

- Involvement in the dialogue **exceeded the expectations** of participants and they found it an interesting, engaging and enjoyable experience. Some questioned how to be more involved in similar activities in the future, while others were left wanting to find out more.
- Recognising that NMH is an extremely complex and vast topic, the dialogue was praised for being conducted in a way that was **understandable.**
- The dialogue presented people with a new opportunity to think about NMH, and there were even some suggestions that being involved had made **people think about their own health, body and health-related decisions**.
- Participants were surprised by how e**ngaged** and talkative people had been, and how they had enjoyed listening to other people's opinions, finding this eye-opening and making everyone feel like equals.
- The **pace of the workshops** was seen to be about right, as well as the length, though the summit was described by some as too rushed.
- Participants valued the opportunity to **engage with experts**, which aided their thinking and their understanding of the topic. They also enjoyed the **range of activities and exercises** throughout the dialogue- from the carousel activity to the brain quiz.
- Participants recognised **the journey** that they had been on and how this was about learning and the sharing of ideas. They also reflected on how they were thinking very differently at the summit to how they had done at the start of the dialogue.
- There was a general agreement that the **public should be involved** in decisions about science and research. There was also an appreciation for organisations like Wellcome who are engaging with the public to inform decision making.
- When asked to design their own engagement strategy based on a topic of their choice, participants tended to focus on how they would **disseminate the research findings (**rather than how to involve the public in forming research questions). They believed the ingredients for success included **interactive and fun techniques**, and where possible, identification of aspects of the research and its findings which will benefit individuals personally. As well, techniques need to be age appropriate.

Conclusions and next steps

What the dialogue findings mean for what Wellcome's priorities should be

- The public were interested in a wide range of different questions ranging from those around how the brain develops, to those related to personality differences, memories and sleep. Interest was often linked directly to personal experience, while they decided areas of research were important where there was a clear benefit to society.

- While they recognised that Wellcome is in a unique position by being politically and financially independent, the public encouraged Wellcome to leave areas which are already well covered, as well as those where we are close to finding a treatment or cure, to other organisations to fund (i.e. leaving cancer to Cancer Research UK).

- Instead, Wellcome should focus on areas which are under-researched, or more innovative, but importantly those addressing fundamental questions where the findings could be widely applicable to many conditions, and have long-term benefits. It was also felt that the Government (via what it funds) should tackle the short-term prioroties, while bodies like Wellcome should have more flexability and choice in it decides to fund.

- In setting Wellcome's strategy, and deciding which areas of NMH research it funds, the public spoke to a set of underpinning principles. These principles can be broadly grouped as research which focus on:

    - The potential to impact many;
    - Prevention, rather than treatment or a cure (including self-help and self-care);
    - Severe, long-term and/or rare conditions (covering quality of life and including life-limiting diseases and those which might otherwise be overlooked);
    - Alternative therapies;
    - Cost saving to the NHS; and,
    - Increasing our understaning of the brain, with the potential to have a 'ripple' effect.

- Some of these principles are, in some cases, conflicting (concentrate on research that will impact as many people as possible / prioritise research focussed on improving the quality of life for people with severely life limiting conditions). However this in itself demonstrates the public's recognition of Wellcome's priviledged positon, and the emphasis on Wellcome to be broad in its remit. It is important to note that at no point throughout the main dialogue were the public pushed to choose or priorotise these principles[11].

- Other principles are overlapping, for example when discussing whether cannabis can be used to treat certain conditions, participants were attracted to the potential of cannabis as an alternative therapy or treatment *and* how researching cannabis has the potential to make cost savings to the NHS. When discussing the case study around mindfulness, participants were drawn to the potential of this alternative therapy, in terms of cost savings to the NHS *and* the benefit to many people.

- In deciding what it prioritises or funds, the findings from this dialogue suggest that even where Wellcome chooses to fund research into specific conditions, it should do so with the view of creating (and sharing)

[11] At the summit, we did ask people to choose the principle that they identified most with, from a shorter list of five.

widely applicable knoweldge. For example, when talking through the case study about Huntington's disease, participants were keen for the research to take the learnings from gene editing and apply these to other genetic diseases.

- The underpinning principles generated in this dialogue speak to those identified in other public dialogues that have addressed strategic priorities for scientific research. For example:

    - In our dialogue for the Jonn Innes Centre (JIC)[12], there were six areas that the public wanted to see from JIC when taking strategic decisions. In particular, the areas of synergy relate to the idea of preserving the right to do fundamental, curiosity driven research which may not necessarily lead to immediate tangible benefits, and prioritising research with the greatest scope to tackle the most serious, high impact, wide-ranging problems of the world.

    - Similarly, in our research assessing public priorities for research into diet and health which falls within the BBRSC[13] remit, the public identified two factors most important for deciding which research projects should be funded: 1) Prevention of future health problems and public benefit; and 2) Improvements for quality of life, particularly the treatment of life-threatening of life-limiting conditions such as cancer.

What the dialogue findings means for Wellcome's strategic direction

On the whole, the areas identified as most interesting and important by the public (brain development, the nature vs nurture debate), suggest that the public would be supportive of Wellcome continuing to fund fundamental research projects which are broad in scope and have the potential to have a wide reaching impact and a ripple effect (Principle 6).

Reflections on the dialogue format

- The evidence, in the round, suggests that a public dialogue was the right approach to use to address the specific research aims and objectives.

- Participants reported high engagement, and that they found the experience interesting and enjoyable. This level of engagement, which contributed towards the success of the workshops, as well as the level of detail elicited through the research activities and the different stimulus used, would not (in our view) have been possible via more standard research methods such as discussion groups or surveys.

- The experience heightened participant interest in the topics, leaving some keen to be involved in similar activities, some wanting to find out more, and others reflecting on their own behaviour and health-related choices. This finding speaks to Wellcome's commitment to high-quality science education.

- Those involved recognised that the complex topic needed time, and participants felt the length of the workshops (3-hour evening session and a 6-hour Saturday session) was appropriate. We often find this on science related dialogues, given that science is an area that the public have less familiarity with. For example, in our current genome editing dialogue for the Babraham Institute, participants have reported

[12] https://www.ipsos.com/sites/default/files/publication/1970-01/sri-john-innes-centre-public-dialogue-strategy-2015.pdf
[13] https://bbsrc.ukri.org/documents/diet-report-pdf/

that the issues are complex and require time – both to understand the concepts, ask questions of experts and to be provided with a range of examples (case studies) before they are fully able to grasp the content.

- Participants viewed the dialogue with experts as engaging and in particular were stimulated when the experts interjected and asked questions and probes to expand on their initial ideas. This unique feature of public dialogue was felt to aid both thinking and their understanding and is often the case for dialogues about science and scientific research.

- Participants also reflected on how their thinking had evolved throughout the course of the dialogue events, and they spoke to how they benefited from the dialogue 'journey', which involved learning and being exposed to new areas and ideas, as well as the views of others. Given the importance of unravelling questions and areas the public are interested in, our feeling is that it was important to expose people to a range of areas and also to give them time to reflect and consider what they saw as important as their knowledge increased.

- The choice and range of techniques appeared to work well too, The carousel format, used in the research summit with participants moving around a room discussing different questions at three 'stations', was also complimented for how it allowed for a good moving pace and meant people did not have to discuss areas for too long. The case studies, used as the bulk of the Saturday all-day event stimulus, brought the science to life and moved people from the overall to more specific areas. The actors and the quiz provided light relief and welcome 'breaks' in an otherwise demanding day on the participants.

- While it is can be difficult in the development of materials to balance the complexity of the issues with the need to communicate succinctly to the public, the materials used did manage to achieve this balance. They can therefore act as a useful benchmark for materials development in future.

- The scope of the dialogue – with such an open question - was fairly broad. While overarching principles to guide Wellcome's strategy have been identified, the public may feel able to give more specific direction on a narrower topic. However, given how early in the public engagement process this dialogue took place, the wide range of questions and ideas generated may not be a problem for Wellcome.

- The exercises where participants generated their own questions[14] suggest that topics which have a self-help element, as well as a preventative angle, would work well in future public engagement exercises. They are likely to be relatable to a range of publics, regardless of age, and other characteristics. As well, such topics, and indeed the research which might come about from these, are also appealing for the potential to provide cost saving solutions to the NHS, as well as avoiding the reliance on medication and drugs via the development of alternative therapies.

- The general agreement that the public should be involved in decisions about science and research, coupled with an appreciation for organisations like Wellcome who are already engaging with the public to inform decision making, is helpful for Wellcome in justifying *why* it should engage with the public.

[14] Participants suggested lots of questions via the Brain post-it note diagram and a handful of these were taken to the summit, from which participants voted to discuss three in more detail: How does your lifestyle (diet, exercise, drugs) affect the brain? Why do we make the decisions we make? Can cannabis be used to treat certain conditions?

Appendices

Appendix 1.1: Evening workshop discussion guide

Public dialogue to uncover what matters to the public in neuroscience and mental health (NMH)?

Discussion Guide for the evening workshop

Event 1: evening session- 6pm-9pm

Note to facilitators:

- Refreshments/ food will be served as participants arrive.
- Hostessing will be provided at each venue.
- At arrival, participants will be given a consent form to sign, and a name sticker (each will be numbered 1 or 2 – as participants will be allocated a table prior to the group). Participants will be asked to complete a pre-task exercise. The pre-task will ask about their general awareness, and interest and understanding of mental health and neuroscience –Questionnaire with unique identifier for tracking views later, plenary presentation
- Incentives will be given at the beginning or at the end of the event
- Make sure the tables are as far as possible from each other, and that there is enough space to fit 12 people around each table.
- Set up the 'brain gallery': if possible, stick the Wellcome Collection prints on a wall in the room where refreshments are served, and the brain diagram poster in the room where the group will take place.
- Have a discussion with the researchers about what we expect their involvement to be

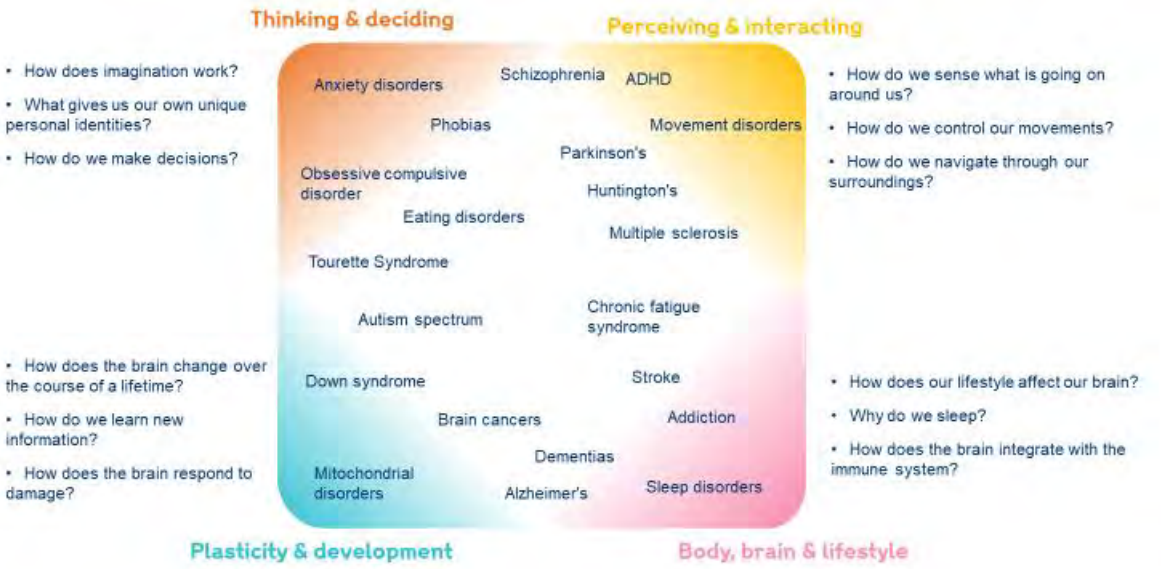
Time	Discussion area	Question areas and materials
6-6.30pm	**Introduction** **Warm up**	**At arrival**: explain each participant that they have been allocated to a table- 1 or 2 and ask participant to sit down and complete the pre-task exercise (once complete, they are welcome to look around the room until the other participants are done). **Plenary presentation:** framing the study. • Aims of the dialogue and plan for the evening • Introduction to dialogue question ***"What matters to the public in neuroscience and mental health?",*** which we will keep up on posters around the room to remind people throughout. Brief introduction to the aims of the dialogue (Ipsos MORI). What areas the public support, what areas are less desirable. • Ipsos MORI team, Wellcome (and scientists/researchers?) to introduce themselves. Housekeeping • Introduction to the brain gallery, including the diagram, where participants are welcome to add questions and thoughts (using post-it notes) to this throughout the workshops at any point **Tables:** • Introduction to each other (name, what's a typical day like for you, something interesting about yourself)

		• Warm up: *When you think about science, what words come to mind? What difference types of scientific research have you heard of/are you interested in?* (WRITE RESPONSES ON FLIPCHART)
6.30-6.45pm	**Gathering spontaneous views on NMH**	**Tables:** The key question of the research is "What matters to the public in neuroscience and mental health?". As we have just heard, Wellcome is shaping its strategy with regards to neuroscience and mental health research that it funds. We want to start by talking about these issues broadly, before hearing more later about some of the specifics. FACILITATOR COLLECTS THOUGHTS ON FLIP CHART: • *What is your brain and what does it do?* • *What is your brain responsible for? How does it affect your wellbeing and mood?* • *Why is having a healthy brain important?* • *How can circumstances and life experiences affect your brain?* (If not already covered/ if time*) What are the effects of having a brain disorder/disease? What happens when the brain doesn't function properly? How does your wellbeing and mood affect your brain? What kinds of things you can do to keep your brain healthy?* ASK PARTICIPANTS TO WRITE A QUESTION OR THOUGHT THEY HAVE ABOUT THE BRAIN ON A POST-IT NOTE AND STICK IT ON THE BRAIN DIAGRAM POSTER
6.45pm-7.15pm	**Introducing Wellcome**	**Introduction to Neuroscience and mental health video** https://www.youtube.com/watch?v=MZ_dIujvRQ0 **Presentation: Overview of Wellcome and its NHM work (20 mins max)** (FACILITATOR TO INTRODUCE PRESENTATION AND TELL PARTICIPANTS WE HAVE LEFT TIME FOR QUESTIONS AFTER THE PRESENTATION) - Wellcome to explain what is in scope and out of scope (Dementia, Depression and Anxiety and why) - Wellcome to illustrate the diseases and disorders affecting the brain mapped to 4 areas (Figure 2 from ITT) - Wellcome to explain how it funds NHM research (response mode model) - (Linked to NHM) Wellcome to explain what fundamental scientific research is – what kinds of questions are answered through this. Provide an example, or two, of Wellcome's work in this area - (Linked to NHM) Wellcome to explain what applied scientific research is – what kind of questions are answered. Provide an example, or two, of Wellcome's work in this area. Q&A to follow presentation
7.15pm-7.30pm **BREAK 15 min**		

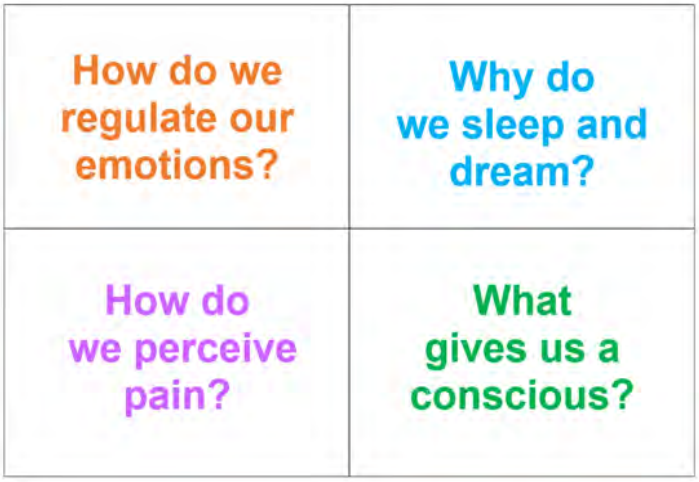
7.30pm-8.40pm	**Reflections and deepen participants' understanding of NMH**	Session to start with a simple video of how the brain works (introducing functions) - https://www.youtube.com/watch?v=pRFXSjkpKWA **Tables:** • Discussion of video: Any surprises, concerns, hopes? • Participants to be given handout of Figure 2 - participants to circle the top five areas of research or diseases they are most interested in - participants to circle questions where they are the most interested - participants are free to add questions/disorders that they are interested into the sheet - participants to then talk I pairs about why they have chosen those areas of research/ questions - each pair to report to the group what they have discussed **THROUGHOUT THIS DISCUSSION, FACILITATORS/ WELLCOME STAFF TO WRITE SOME OF THE PARTICIPANTS QUESTIONS ON A POST IT AND STICK THEM ON THE BRAIN DIAGRAM TO ENCOURAGE PARTICIPANTS TO DO THE SAME** **(at approx. 8pm) CARD SORT EXERCISE**: Facilitator holds a card and to ask the group to sort them and hang them up on an imaginary washing line. One end of the line to read "Fundamental research" and the other end to read "Applied research". Facilitator sticks short definitions for each term underneath fundamental research and applied research cards. FACILITATOR PLACES 4 CARD (2 FUNDAMENTAL/ 2 APPLIED) ON THE LINE – THEN HOLD THE REMAINING CARDS ONE BY ONE AND ASK PARTICIPANTS TO DO THE SAME All the cards are related to work that is already, or could be, funded within Wellcome's NMH research. Exercise to be assisted by scientist/researcher. • Facilitator place cards on the washing line • Discussion following exercise around the beneficiaries, timelines, associated risks. • If a card prompts a particular strong response/ interest, the facilitator will make a note of it. • Please note you don't have to go through all the 16 remaining cards FACILITATOR TO PROMPT THROUGHOUT: • Why do you think this? • Do you think it is important/interesting? • What makes this more or less important compared to other things? WELLCOME STAFF/ RESEARCHERS TO HELP ANSWER PARTICIPANTS' QUESTIONS (but it is fine to say you don't know the answer). Topics/ questions to cover include: **Fundamental Science Research Questions:** How do we regulate our emotions? Why do we sleep and dream? How do we perceive pain? What gives us a conscience?

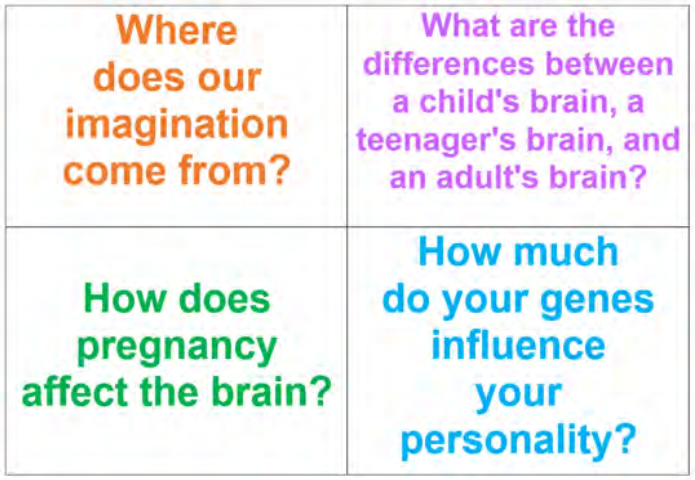
		Where does our imagination come from? What are the differences between a child's brain, a teenager's brain, and an adult's brain? How does pregnancy affect the brain? How much do your genes influence your personality? How do we store memories? Why do we feel pins and needles? **Applied Science Research Questions:** What causes borderline personality disorder (BPD)? How can we treat schizophrenia? How can we improve life expectancy for people with brain cancer? How can we treat eating disorders? Why does obsessive compulsive disorder (OCD) develop? How can we prevent Parkinson's disease? Why do treatments for ADHD work for some people, but not for others? What is the best way to get over jet lag? What causes autism? Why do some people recover from brain injuries, while others don't?
8.40pm-8.50pm	**Plenary: Summarising most important issues for participants.**	Facilitators summarise what was discussed during the table discussions. One facilitator to summarise some of the post-it notes on the brain diagram Opportunity too for the researchers to answer any questions that have not been covered,
8.50-9pm	**Explanation of the homework and close**	Provide information about event 2 and September summit Homework exercise explained: • Facilitators to hand out homework sheet • talk to friend / family member about NMH and find out what matters to them; or, • go online and find out a bit more about some areas of NHM that interests you. Thank participants and hand out incentives for a prompt 9pm finish

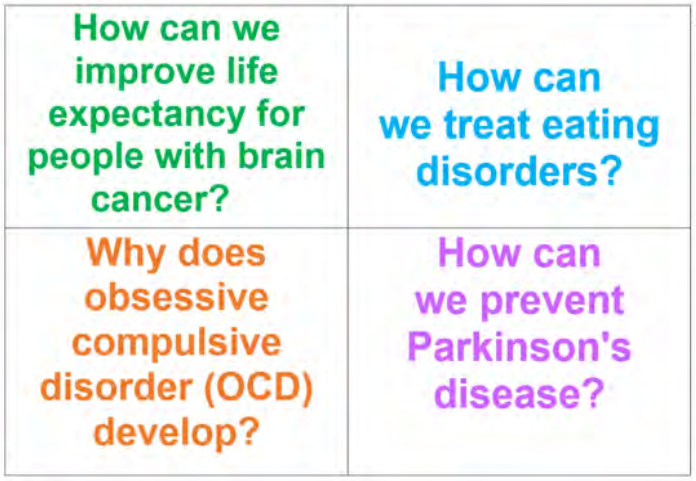
Appendix 1.2: Diseases and disorders handout (used in the evening groups)



Appendix 1.3: Fundamental and Applied card sorting exercise







Appendix 1.4: Tracking questionnaire

Ipsos MORI

wellcome

What matters to the public in neuroscience and mental health?

Questionnaire

Please write in your full name

FOR EACH QUESTION PLEASE TICK ✓ ONE ANSWER ONLY

Q1 How interested are you, in general, in science and health research?

Very interested	Fairly interested	Not very interested	Not at all interested	Don't know
☐	☐	☐	☐	☐

Q2 How confident do you feel talking about science topics?

Very confident	Fairly confident	Not very confident	Not at all confident	Don't know
☐	☐	☐	☐	☐

Q3 How much do you feel you know about neuroscience and mental health research?

I know a lot about it	I know a fair amount about it	I know just a little bit about it	I have heard of it but know nothing about it	I have never heard of it
☐	☐	☐	☐	☐

Q4 How interested are you in the brain and how it works?

Very interested	Fairly interested	Not very interested	Not at all interested	Don't know
☐	☐	☐	☐	☐

Q5 How interested are you in brain diseases and brain injury?

Very interested	Fairly interested	Not very interested	Not at all interested	Don't know
☐	☐	☐	☐	☐

Q6

How interested are you in mental health and wellbeing?

Very interested	Fairly interested	Not very interested	Not at all interested	Don't know
☐	☐	☐	☐	☐

Q7

How likely are you to seek out information about neuroscience and mental health?

Very likely	Fairly likely	Not very likely	Not at all likely	Don't know
☐	☐	☐	☐	☐

Q8

How likely are you to discuss topics relating to neuroscience and mental health with others?

Very likely	Fairly likely	Not very likely	Not at all likely	Don't know
☐	☐	☐	☐	☐

Q9

How important do you think it is to fund and support neuroscience and mental health research?

Very important	Fairly important	Not very important	Not at all important	Don't know
☐	☐	☐	☐	☐

Q10

To what extent, if at all, do you think the public should be engaged in setting the direction of science and health research?

A lot	A little	Not at all	Don't know
☐	☐	☐	☐

Appendix 1.5: Homework

Ipsos MORI

wellcome

What matters to the public in neuroscience and mental health?

Homework exercise

Before the Saturday workshop, could you please go home and think of the following:

- talk to friend / family member about NMH and find out what matters to them, and/ or
- go online and find out a bit more about some areas of NHM that interests you.

My notes:

Appendix 1.6: Saturday workshop discussion guide

Event 2: Saturday workshop – 10am-4pm

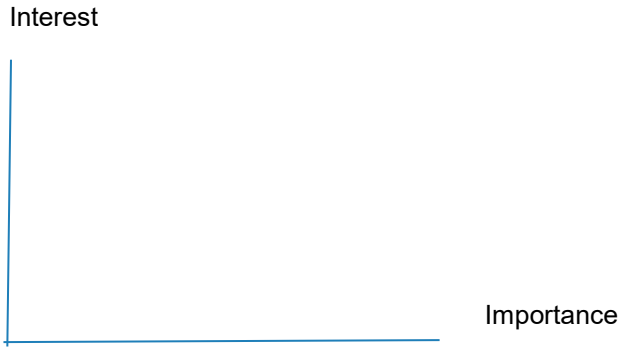
Note to facilitators:

- Refreshments/ food will be served as participants arrive. Lunch is scheduled at 12.25pm, and a coffee break at 2.45pm
- Hostessing will be provided at each venue.
- At arrival, give participants a name sticker and remind them which table they've been allocated to.
- Incentives will be given at the beginning or at the end of the event.
- **Make sure the tables are as far as possible from each other, and that there is enough space to fit 12 people around each table.**
- Set up the 'brain gallery': if possible, stick the Wellcome Collection prints on a wall in the room where refreshments are served, and the brain diagram poster in the room where the group will take place.
- Have a discussion with the experts about what we expect their involvement to be: explain that they can get involved in the discussions, especially during the case study exercise, by opening with 'can I just offer something to help you think about…' Explain them that they will need to be silent throughout the mapping/ refining principles exercises (unless the participants ask them a direct question).
- An improvisational acting team will perform a series of sketch at two points throughout the day, to help bring to life the case studies and highlight emerging points of view, as well as providing stimulation for plenary discussions.
- Voting pads will be used for the brain quiz exercise.
- **Make sure to take pictures of the brain diagram/ flipcharts before leaving.**

Time	Discussion area	Question areas and materials
10-10.15	**Introduction** *Plenary*	• **Arrival and registration** • **Introductions: revisit introductory slides,** and additional slide on the key aim of the workshop/ timetable for the day • **Introduce WT staff, expert(s), note-takers and actors** • **Quick presentation from experts- 5 minutes** • **Questions or concerns** • **Remind participants of brain diagram**- tell participants to write down any thoughts or questions on a post -it note and stick in on the diagram. Tell them that, if we have time at the end of the day, we will talk through their questions/thoughts together (but that in any case, we will look at those after the event and include them in our report).
10.15-10.35	**Revisiting key concepts**	**Tables:** • Review of homework task – what did people look into, or speak about, and why? • (if time) Revisiting key ideas from Event 1 – key concepts of NMH, what surprised the/ interested them from last time? What one thing did they learn that they didn't previously know? Have their opinions changed after Event 1?

10.35-10.50	**Quick knowledge quiz** *Plenary*	**Plenary: into the world of the brain** Assessment of basic knowledge exercise. Please note that this is an energizer and not intended to be a test. Participants are given voting pads and asked to vote on 10 simple multiple-choice questions about the brain. FACILITATORS READ THROUGH EACH QUESTION AND ASK PEOPLE TO VOTE. WELLCOME STAFF/ EXPERTS TO TALK THROUGH THE CORRECT ANSWERS. ALLOW PARTICIPANTS TO ASK QUESTIONS BUT KEEP TRACK OF THE TIME (1.5 PER QUESTION).
10.50-11.10	**Discussing the big questions** *Tables*	**Tables:** FACILITATOR READS QUOTE BELOW "The research work… is expected to yield much of purely technical interest which simply adds to the world's scientific knowledge, but at the same time a very large part of such research work must have a very practical bearing on the great problems affecting the life, health and well-being of mankind." Henry Wellcome FACILITATOR EXPLAINS THAT WE'RE NOW GOING TO SPEND A BIT OF TIME THINKING MORE BROADLY ABOUT CURRENT SOCIETAL AND HEALTH CHALLENGES, AND HOW THESE MIGHT AFFECT OUR BRAIN AND MENTAL HEALTH *(It is possible participants are naturally drawn to discuss MH rather than MH in relation to neuroscience. Try and bring back the discussion to neuroscience by asking them how those challenges could have an effect on our brain)* • What do you think are the (current or future) challenges/ problems are going to affect our health and wellbeing in the future? • What will cost society the most money and effort if we don't sort them? • How do you think those challenges/ issues will impact our brains? • How do you think research could alleviate those issues? What type of research? • Thinking about what was discussed in event 1, what are the benefits of NMH research in relation those issues? LET PARTICIPANTS DISCUSS THEIR THOUGHTS, THEN IF THEY STRUGGLE TO COME UP WITH ANY CHALLENGE, SHOW PARTICIPANTS THE 'BIG QUESTIONS' CARDS • Any other challenges • After discussed all of those challenges- if you were in charge of all the Wellcome brain research, what kind of research do you think would best help us address all the challenges that we face? • What is important to take into consideration when submitting different projects to you? IF PARTICIPANTS STRUGGLE, FACILITATOR CAN GIVE ONE OR TWO EXAMPLES – *e.g. Tackling issues that affect high numbers of people (but to a lesser extent) or tackling the issues that affect low number of people (but to a greater extent), find a specific area to make a big impact or support numerous areas at a smaller scale etc* (if not already discussed and if time)

		FACILITATOR TO READ LIST OF TOPICS/ QUESTIONS DISCUSSED DURING EVENING EVENT • Which of these are more important given the challenges of the future? FACILITATOR TO WRITE DOWN THOUGHTS ON FLIPCHART
11.10-11.20	**SHORT CONVENIENCE BREAK** *(make sure to tell participants this is a short break and they need to be back at the table in 10 minutes)***.**	
11.20-12.15	**Case studies- 1** *Tables*	**Tables:** The case studies will be rotated for each event. Please refer to the 'case studies allocation sheet' to check the order in which you should present the case studies) • **Introduce one case study:** FACILITATOR OR EXPERT TO READ THROUGH THE FIRST CASE STUDY • **Discuss the case study** using the questions/ prompts below. • **Repeat for case studies 2,3 and 4** • **Allow 10/15 minutes per case study** **For each case study:** • Did everything make sense? Do you have any questions? • What interests you about this case study? If this doesn't interest you, why? • Anything confusing? • What surprises you about this? • Any concerns? • Who will this benefit? • Do you think this is useful research to do? If not, why? • How could this research be put to use in a way which will do the most good? • What future social changes might this bring about? • Is this short term/ long term? • Are there other studies you'd like to see in that area? • MAKE SURE TO READ THE PROBES SPECIFIC TO EACH CASE STUDY *Get through 4 case studies*
12.15-12.25	**ACTORS TO ROLE PLAY TABLE DISCUSSIONS** (plenary)	
12.25-13.15	**LUNCH (50 min)**	
13.15-14.10	**Case studies- 2 and discussion** *Tables*	**Tables:** **(13.15-14.10)** **Same as above**- the tables discuss the remaining case studies (no need for the facilitator to introduce one case study this time) *Get through the other 4*
14.10-14.35	**Mapping the case studies**	**Tables- 2.10-2.25**

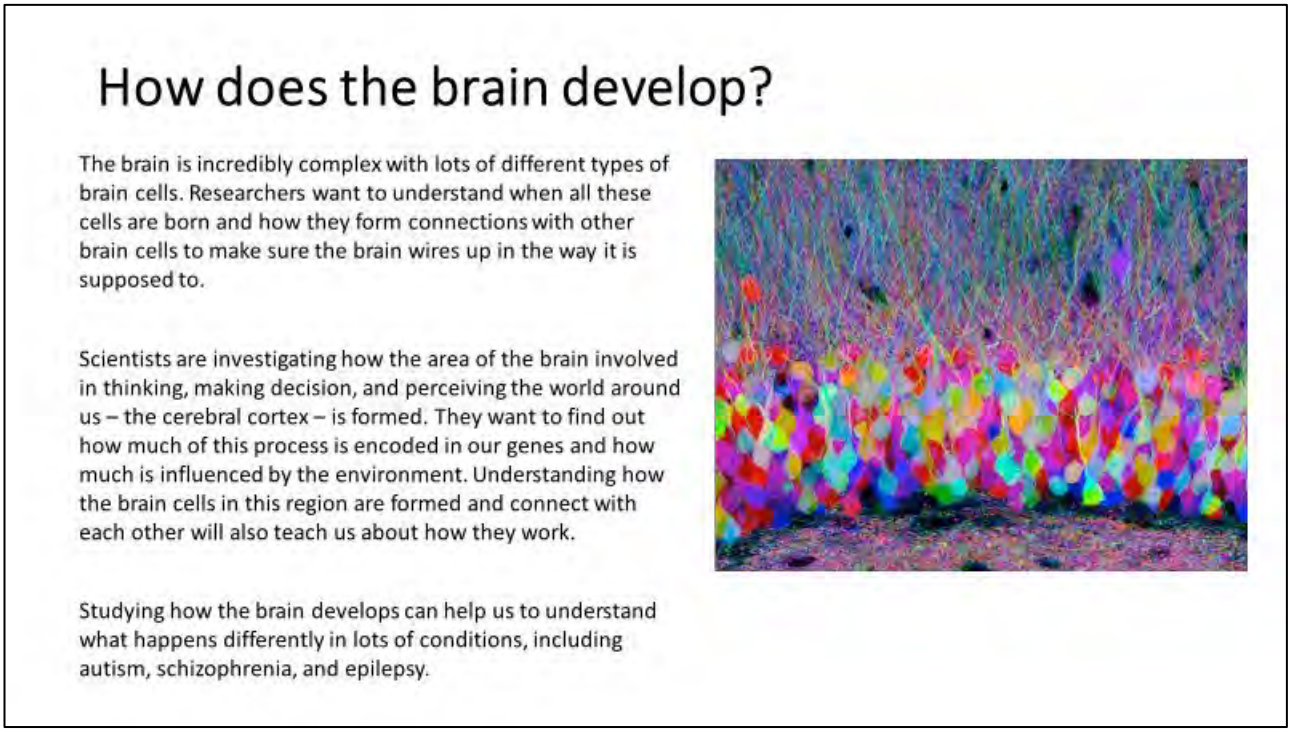
	and uncovering principles *Tables and plenary*	**Map case studies (once all case studies have been discussed)** FACILITATOR DRAWS A GRID ON THE FLIPCHART AND ASK PARTICIPANTS WHERE THEY THINK EACH CASE STUDY SHOULD GO. IN ADDITION TO THE CASE STUDIES, FACILIATOR CAN ASK THE PARTCIPANTS TO THINK OF OTHER AREAS OF RESEARCH. IF POSSIBLE, STICK TWO FLIPCHART PAGES NEXT TO EACH OTHER AS THE AXIS NEEDS TO BE BIG  FACILITATOR ASK PARTICIPANTS TO PLACE CASE STUDY CARDS ON THE AXIS *Can use these questions as prompts but the main prompts will be the spectrum* • Place case studies on spectrum – according to the 2 axes • How are you defining what you mean? **Discuss why and give reasons** • Which areas would you like to improve your understanding of? Why? • **Biggest improvement to the understanding of life and health:** when Wellcome funds science, they think about whether the proposed projects will contribute to the understanding the brain and improving health (among other things) – which of these would you judge to have the greatest contribution? • What impacts and improvements are they imagining? For who? short term/ term etc *Facilitator to tease out consensus or areas of disagreement and the principles people are using if they differ within the group.* *At this point – experts don't challenge/ correct – they give information during the case studies sessions, but this is a part when they remain silent observers and let participants do the mapping.* **Plenary- 2.25-2.35** **EACH FACILITATOR PRESENTS BACK THEIR TABLE'S GRID TO THE WHOLE GROUP.** ONE FACILITATOR MODERATES/ASK QUESTIONS, WHILE THE OTHER STARTS IDENTIFYING PRINCIPLES AS THEY LISTEN AND WRITE THEM DOWN ON FLIPCHART (I.E. START GATHERING WORDS THEY HEAR AND 'TRANSLATE THEM INTO PRINCIPLES' *e.g.* "alleviating suffering of the most number of people" /

		"addressing diseases that are scariest" or "stopping us losing capacity as we age" etc). *Identify if consensus, why are your tables different from each other?*
14.35-14.45	**ACTORS TO ROLE PLAY TABLE DISCUSSIONS** (plenary)	
14.45 – 15.00	**Break** **(DURING THE BREAK, EACH FACILITATOR SWAPS NOTES WRITES THE LIST OF PRINCIPLES THAT CAME OUT DURING THE LAST EXERCISE ON THEIR FLIPCHART)**	
15.00 – 15.30	**Identifying and refining Principles** *Tables*	**Tables** FACILITATOR AT EACH TABLE ASK PARTICIPANTS TO IMAGINE THEY ARE IN CHARGE OF FUNDING NMH RESEARCH/ AND IMAGINE WHICH PRINCIPLES THEY WOULD USE WHEN THEY COMMISSION THE RESEARCH. FACILITATOR SHOW THE INITIAL LIST OF PRINCIPLES ON THE FLIPCHART AND EXPLAINS THESE HAVE CAME UP WITHEN MAPPING THE CASE STUDIES PROMPT THEM WITH THE LIST MADE IN THE PREVIOUS EXERCISE: • Do you agree with this principle? Why? Why not? • Do you think this principle is **more/less important than others?** Why? Why not? • Do you think some people might disagree with this principle? Why? Why not • Are they any other principles you think are important? AND ALSO USE THE FOLLOWING IDEAS IF THEY GET STUCK: 1. *Tackling issues that affect high numbers of people (but to a lesser extent) or tackling the issues that affect low number of people (but to a greater extent)* 2. *Finding things out about the brain that could help us understand aspects of a lot of diseases (e.g. memory, sleep) vs focusing on a specific disease* 3. *Finding things out about things that affect everyone (sleep, memory, etc) vs finding things out about specific diseases* 4. *Things that affect future generations more or our generation?"* 5. *Finding treatments not involving drugs (e.g. mindfulness for mental health)* 6. *Understanding topics or diseases where we have a very poor understanding currently (e.g. mental health, sleep, etc) vs focusing on areas where we have more knowledge* 7. *Find a specific area to make a big impact or support numerous areas at a smaller scale?* 8. *Things that could ease symptoms (e.g. pain, fatigue) vs things that improve health?* 9. *Ensuring quality of life vs longer life* 10. *Things that patients or sufferers have more control over vs less? (in the perception of the group, e.g. things amenable to talking cures vs medical cures)* 11. *Things where people could benefit simply from applying scientific knowledge that's already known, in the view of the participants (e.g. in previous dialogues, people felt there were practical cures for obesity that could be applied, and did not prioritise further research)*

		12. *Things that will cost us as a society most money if we don't cure them. E.g. NHS obesity or diabetes and neurological impacts* 13. *Things that will cost the world – things that relate to the big challenges they talked about upfront* 14. *Funding prevention and treatment for conditions vs enhance what the brain could achieve (unlocking its full potential) → prevention vs treatment/cure* *This will help tease out principles and prioritise them.* (if time) FACILITATOR TO LOOK BACK AT THE 'CASE STUDIES MAP' AND ASK PARTICIPANTS WHETHER, NOW THEY HAVE THOUGHT AND IDENTIFIED SOME PRINCIPLES, THEY ARE STILL HAPPY WITH THE WAY THE CASE STUDIES ARE MAPPED. • Would you map them differently? If not, why not? • (if time) What do you think WT's top 5 principles should be? The same? Different? Why? Why not?
15.3 – 15.50	**Funding Exercise** *Tables and Plenary*	**Tables** **Budget/token allocation** EACH PARTICIPANT IS GIVEN 5 STICKERS. ONE FACILITATOR EXPLAINS THAT THERE ARE TOKENS AND REPRESENT 'THEIR BUDGET'- THEY HAVE TO DECIDE WHICH CASE STUDY THEY WANT TO FUND. THEY CAN DISTRIBUTE THEIR TOKENS AS THEY WISH- ALL 5 FOR ONE CASE STUDY OR SPREAD THEM ACROSS SEVERAL CASE STUDIES. ASK THEM TO HAVE A THINK AND TO USE THE PRINCIPLES WE HAVE DISCUSSED TO GUIDE THEIR DECISIONS. EACH PARTICIPANT TO STICK THEIR STICKERS ON A CASE STUDIES SUMMARY SHEET. *Leave 5 minutes to participants* FACILITATOR THEN GO AROUND THE TABLE AND ASK EACHPARTICIPANT HOW THEY'VE SPENT THEIR BUDGET FACILITATOR THEN RANK EACH CASE STUDY ON THE MAP (1 NEXT TO THE CASE STUDY CARD WITH THE MOST STICKERS- 8 NEXT TO CASE STUDY CARD WITH THE LESS STICKERS). THEN, WE LOOK AT WHICH CASE STUDIES HAVE COME ON TOP/ AT THE BOTTOM. SEE IF THIS CORRESPONDS TO THE MAPPING • Any surprises • Does this reflect your principles? • Any final advice for WT? **Plenary** (5/10 min) EACH FACILITOR TELLS THE WHOLE GROUP WHICH 3 CASE STUDIES CAME ON TOP AT EACH TABLE • Any surprises? Thoughts (IF TIME) ASK EXPERTS/WT STAFF TO REFLECT ON THIS/ HOW THIS MIGHT FIT WITH THEIR STRATEGY

15.50-15.55	**Questionnaire**	(5 min) Final exercise… • Complete tracking questionnaire • Explain participants that it is the same questionnaire as the one they had to fill before the evening group. We want to see whether their views have evolved.
15.55-16.00	**Conclusion**	**Wind down** • (only if time) Look at the questions brain diagram/ and compare with questions from the evening group • Thank you and close • Hand out post-event evaluation questionnaire
16.00-16.10	Recruitment for the post-research summit on **September 7th** • Event to be held at the Wellcome offices from 12pm to 3.30pm (walking distance from Euston and Kings Cross/St Pancras stations) • Travel expenses will be reimbursed and a thank you payment of £100 will be given • Please note that we will only recruit 6 participants from this group. We want to make sure to have a mix of participants • If interested, please write your contact details on post-research summit contact details form	

Appendix 1.8: Case studies discussed with the experts



How does the brain develop?

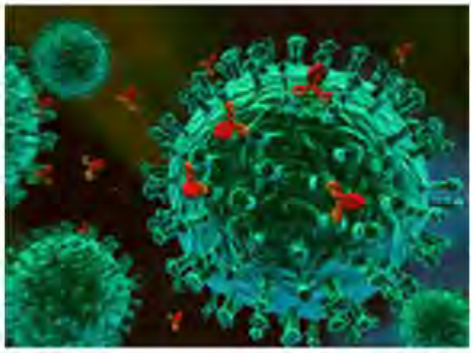
The brain is incredibly complex with lots of different types of brain cells. Researchers want to understand when all these cells are born and how they form connections with other brain cells to make sure the brain wires up in the way it is supposed to.

Scientists are investigating how the area of the brain involved in thinking, making decision, and perceiving the world around us – the cerebral cortex – is formed. They want to find out how much of this process is encoded in our genes and how much is influenced by the environment. Understanding how the brain cells in this region are formed and connect with each other will also teach us about how they work.

Studying how the brain develops can help us to understand what happens differently in lots of conditions, including autism, schizophrenia, and epilepsy.

How do emotions affect the body's immune system?

We know that mental outlook affects the body's response to disease. For example, having a positive emotional state is linked with better outcomes for cancer patients. Researchers are interested in finding out how the brain can affect the body's ability to fight off disease.



Scientists found that stimulating an area of the brain associated with a feeling of reward reduces the size of tumours in the lungs of mice. This is because stimulating this area of the brain sends signals to nerves throughout the body, and these nerves affect the immune system. Researchers are now investigating how these nerves communicate with the immune system.

This research will improve our understanding of how the brain interacts with the immune system, and this could ultimately lead to new treatments for a wide range of diseases, including cancer and multiple sclerosis.

Which part of the brain controls sleep?

We know that sleep is essential for survival. Sleep deprivation can affect your ability to learn, your memory, and your emotions.

Scientists have identified an on/off switch for sleep in the brain. They found a group of brain cells in the brains of flies which are active during sleep and silent when the flies are awake. Now they are investigating what switches these brain cells on or off.

Sleep problems are at the root of conditions such as insomnia and narcolepsy. They are also common in a lot of other brain disorders including schizophrenia and Parkinson's disease. Understanding the brain signals which send us to sleep could help develop new treatments for these conditions.

How can we predict who will lose their sight?

Age-related-macular-degeneration (AMD) is a very common cause of blindness. Some patients with the disease lose their sight very quickly, while others develop the disease more slowly. When patients are told they have this condition the doctors can't predict when they will start to go blind, if at all.

Researchers are teaching computers to analyse detailed images of the inside of the eye from people with and without AMD. This will help the researchers develop a method to predict who will lose their sight quickly. This could also lead to new treatments for the disease.

Scientists also hope this will provide clues about how the disease develops, which could lead to new treatments.

How can we treat Huntington's disease?

Huntington's disease is an inherited condition which develops between the ages of 30-50. A faulty gene causes brain cells to die, leading to problems with controlling movements and emotions and a loss of thinking ability. The condition gets worse over time, and patients die typically 15-20 years after diagnosis. Currently there is no cure for this disease.

Scientists have developed a treatment which can silence the gene causing the condition. They are trialling this treatment in patients to find out more about how it affects the body and, to identify the best time to give the treatment.

How can we stop chronic fatigue after a stroke?

After a stroke, many people experience a feeling of fatigue which lasts for months or years. Simple everyday actions require a lot of effort. Scientists are working to find out if this is caused by a change in the way the brain processes sensations from the muscles.

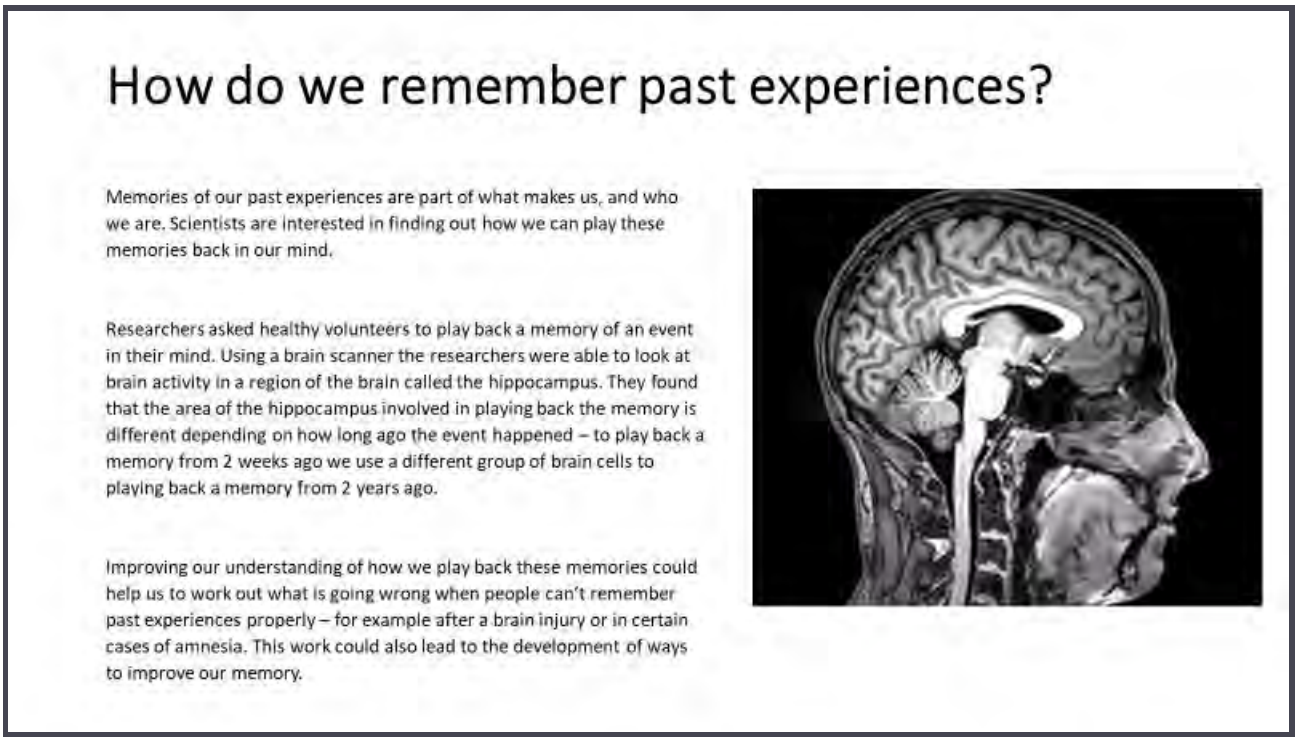
Normally, simple actions don't cause fatigue because the brain is expecting to feel a sensation associated with muscles contracting . And the brain suppresses these sensations. This allows us to carry out everyday tasks without high effort. Scientists are investigating whether a stroke can cause the brain to lose its ability to suppress this sensation. They will use this information to develop treatments for this feeling of chronic fatigue.

Fatigue is a common complaint in a number of different diseases and disorders of the brain, so these findings could be applied to people with other conditions. Understanding what is causing this feeling of fatigue might lead to the development of new treatments.

Does mindfulness work?

Mindfulness is a popular meditation technique that involves focusing attention on the present moment. There are reports that mindfulness can improve mental wellbeing.

Scientists want to work out if mindfulness can be an effective method to protect against mental health problems. They are studying the effects of mindfulness training in young people to find out how mindfulness changes the brain. They want to use this information to develop better interventions.



Appendix 1.7: Post-research summit discussion guide

Public dialogue to uncover what matters to the public in neuroscience and mental health (NMH)?

Post-research summit- Discussion guide

September 7th 12.30pm to 3.30pm

To note:

- Participants will arrive at 12pm. Lunch will be served then, ideally outside of the room. Lydia to sign people in and get them to sign consent forms.
- A selection of the 'brain questions' from the post-it notes will be printed on A3 cards and displayed around the room.
- Participants will be split in three tables, mixed up by location, age and gender.
- Michelle to chair/ Camille, Anne and Anna to facilitate/ Lydia to host.
- Tasks to be assisted by Wellcome staff and possibly other experts.
- 1 expert/ researcher per table

Time	Discussion area	Question areas and materials
12.30pm to 12.40pm	**Introduction** and warm up	**At arrival into the room**: explain each participant that they have been allocated to a table- 1 or 2, 3 **Plenary presentation:** • Brief reminder of the aims of the dialogue (Ipsos MORI). What areas the public support, what areas are less desirable. • Aims of the summit • Ipsos MORI team, Wellcome (and scientists/researchers) to introduce themselves.

		• Housekeeping **Tables:** • Introduction to each other (name, what's a typical day like for you, something interesting about yourself)
12.40pm-13:15	**Replay, validate and refine findings**	**Plenary** **Ipsos chair to present slides summarising key emerging findings (15 minutes):** • what came up in general discussions • how discussions differed according to age and other factors (location as a possibility here) • what came out when we discussed the case studies: importance vs interest • explore differing views on the case studies (e.g. on mindfulness- don't really believe the science/think of the savings for the NHS and potential for saving mental health and wellbeing) • explore emerging principles **Wellcome to present a few of slides about (5 minutes):** • how findings are going to be used • overall engagement strategy (who else has been/will be engaged and how) • wider benefits of the research **Tables** **Reflection on the findings (15 minutes)** • Any surprises/ thoughts? • These are the emerging insights from across all the three reconvened events we ran o do you feel this matched what you discussed at your table? if so, how well have we managed to correctly interpret your views and thoughts? • Were there other important areas discussed in your group which have not been captured here? • Is there anything else you would have liked to discuss? • What are your thoughts on the age/other differences identified? Why do you think these differences might exist? • EACH FACILIATOR GIVES PARTICIPANTS A HANDOUT WITH TOP 5 PRINCIPLES IDENTIFIED: Explain that these are some of the underlying research funding principles or values that participants across the three locations spoke to during discussions, mostly on the second event. Explain that these evolved during discussions, but were not necessarily offered by participants in this way. Explain that as they evolved, they were sense checked with participants at the tables they came from. Do they match what you think? Why? Why not? • Ask participants to raise their hand for the principle they think is the most important.
13:15-14:20	**Digging deeper into**	**Tables**

	case studies (1 and 2) **Carousel**	DISCUSS TOP 3 CASE STUDIES IDENTIFIED IN TURN. 20 MINUTES PER CASE STUDY. ONE TABLE ALLOCATED TO ONE CASE STUDY SO PARTICIPANTS WILL HAVE TO MOVE TO A DIFFERENT TABLE EVERYTIME THEY DISCUSS A NEW CASE STUDY. EACH EXPERT/ILLUSTRATOR/ FACILITATOR ALLOCATED TO ONE TABLE/ONE CASE STUDY. FACILITATOR TO BUILD ON WHAT WAS DISCUSSED BY THE PREVIOUS GROUP. **Plenary** At the Saturday workshops, we asked you to discuss eight case studies. We have selected three of those that you found particularly interesting, important or both for this exercise. We want you to re-discuss those topics but also to delve deeper. We want you to think about those studies more broadly- and we have an expert at each table to help you to do so. The aim of this exercise is for you to come up with ideas and questions that interest you– and which could form future funding strategies. • Case study 1 – How does the brain develop? (ANNA) • Case study 2- How do emotions affect the immune system' (ANNE) • Case study 3- 'Which part of the brain controls sleep?' (CAMILLE) **Overview from experts of case study 1,2 or 3 and their wider scope/ implications (3 to 4 minutes)** Expert to discuss the research area more broadly, what has been done, what areas are more advanced, and which areas less? **Discussion with expert and facilitator (15 minutes)** DURING DISCUSSIONS, TABLE FACILITATORS TO START COMPILING A LIST OF POSSIBLE RESEARCH QUESTIONS/AREAS OF RESEARCH ON FLIP CHARTS. FOR THIS ACTIVITY, WE ARE LOOKING FOR EACH GROUP TO BUILD ON EACH OTHER'S THOUGHTS. THE FACILITATOR WILL HAVE TO QUICKLY EXPLAINED WHAT WAS DISCUSSED BY THE PREVIOUS GROUP AND ASK PARTICIPANTS TO DISCUSS WHAT THEY THINK. (Please note that all the probes below don't need to be covered, they are just here pointers) • What interests you about this type of research? • What are the kinds of areas that this research could cover? • Imagine that you get to decide what to research next in this field. What would you want to investigate / research further? • What questions would you want an answer for? ASKS EACH PARTICIPANT TO WRITE 1 RESEARCH QUESTIONS ON A PIECE OF PAPER. THEN DISCUSS • For each question identified: o Why is this important?

		o If there was some research that answered this, what further questions do you have? o Are there other studies you'd like to see in that area? o (if time and not already discussed) Who will benefit from these studies? o (if time and not already discussed What is the potential from doing this kind of research? REPEAT FOR EACH CASE STUDY TO BE DISCUSSED **Plenary** Chair to summarise discussions/ questions raised (5 minutes)
BREAK (10 min) - *encourage participants to look at the illustrations*		
14.30-14.50	**Exploring areas of interest spontaneously raised**	**Plenary** **Walking around the room exercise (5 min)** EACH PARTICIPANT IS GIVEN THREE STICKERS. THEY ARE THEN ASKED TO WALK AROUND THE ROOM AND READ ALL THE 'BRAIN QUESTIONS' DISPLAYED ON THE WALLS (ON A3 POSTERS). THEY THEN HAVE TO DECIDE WHICH QUESTIONS ARE THE MOST INTERESTING TO THEM AND TO STICK THEIR STICKERS ON THOSE QUESTIONS/RESEARCH AREAS (ONE STICKER PER QUESTION). CHAIR LOOKS AT THE 3 QUESTIONS/RESEARCH AREAS WITH THE MOST STICKERS, AND ASK PARTICIPANTS TO SPLIT IN GROUPS DEPENDING ON WHICH QUESTION THEY WANT TO DISCUSS. EACH GROUP GOES TO A DIFFERENT CORNER OF THE ROOM. (Please note each discussion will be carried out standing up and the new mini groups will mix participants from different tables meaning there is some cross pollination throughout the event, exposing people to different views and opinions). **Gathering spontaneous views about the 'brain questions' (15 minutes)** EACH FACILITATOR FOCUSSES DISCUSSES AND PROBES THE PARTICIPANTS WHO HAVE CHOSEN TO DISCUSS THE QUESTION AT THAT STATION. EXPERTS (WHO CAN SPLIT OUT INTO THE 3 MINI GROUPS) CAN ALSO PROBE PARTICIPANTS AND RESPOND TO THEIR QUESTIONS. • What do you understand this question or possible research area to cover? • **Why did you choose to discuss this question or possible research area?** • **Why does this interest you?** • **What do you want to find out more about**? • Who do you think this would benefit? • In which ways do you feel this is important? • Are there other studies you'd like to see in that area? FACILITATOR TO NOTE DOWN DETAILED RESEARCH QUESTIONS/AREAS WHICH ARISE THROUGHOUT DISCUSSION ON THE A3 POSTER.

2.50pm to 3.20pm	**How best to engage the public on NMH**	**Tables** **Evaluating the dialogue process (10 min)** GIVE EACH PARTICIPANT A COLLAGE OF THE DIFFERENT ACTIVITIES FROM EVENTS 1 AND 2 (i.e. made up of photos taken of the actors, table discussions, case study mapping, different flipchart outputs and screen shots of the videos shown) • What did you think of the dialogue? • Were there any activities you liked/ disliked more than others? Why? • What did you think of the information and stimulus provided? (videos, case studies, etc) -PLEASE ALSO PROBE ON ILLUSTRATORS • **At which points did you start to gain a better understanding of NMH research?** • **At which point/s throughout the two events did feel most engaged and why?** • How would summarise to a friend or family member what you've done and what it has been like for you? **Thinking about public engagement in NMH/science in the broader sense (15 minutes)** Now, we would like to think about how best engage the general public in NMH research, and about different engagement strategies. First we want you to think about which part of NMH research where there should be more engagement with other people around. And have a think about if people should be more involved in: o help set and inform the research direction o be involved and engaged in the research itself (e.g. participating in research studies, or doing citizen science, or part of a panel for consultation, etc) o or to be more informed about the research outputs and evidence Then, we want you to pick a topic that you think is important to engage other members of the public about, and come up with your own engagement for it. GIVE PARTICIPANTS A HANDOUT WITH A LIST OF POSSIBLE ENGAGEMENT ACTIVITIES: o Science festival o Documentary o Game (video game or board game – Hellblade is successful game that we funded that teaches players about what it's like to experience psychosis) o Public dialogue o Museum or exhibition o Theatre performance that explores an area of science/research o Pop up exhibition in a public space e.g. shopping centre o Survey to gather public opinion on a topic o Citizen science (e.g. game or app or tools for people to input data or carry out their own science experiments) o Social media

		o Research interest group (group of members of public with interest in furthering a research area) Get participants to work in pairs: • Agree on one area of research you would like to engage others in • Think about *who* you want to engage *how* you want to engage them - raising awareness about your research but also engaging them to make them interested and become informed • Think about the points at which you would want to engage the audience: i.e. at the idea generation stage, proposal stage, initial research, intermediate research, final research, afterwards to tell them about the findings • Think about who, or which groups, you would want to engage and why? PROBE: school children, patient groups, community groups, the general public • Think about hard to reach groups and how you might engage them • Think about the benefits and drawbacks of different techniques **Tables (10 min)** Present back to the group (10 minutes)
3.25pm to 3.30pm	**Close**	**Plenary** Chair summarise what was discussed throughout the afternoon. Wellcome Staff can reflect on this too. Thank participants and hand out incentives for a prompt 3.30pm finish

Appendix 1.8: Brain post-it note questions

Can we replace parts of the brain when they are damaged?

How does our lifestyle (diet, exercise, drugs, etc) affect the brain?

How does technology (phones, TV, computers) affect the brain?

How can we make ourselves smarter, for example through 'brain training'?

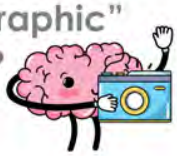
How does hypnosis work?

How do hormones affect the brain?

Can cannabis be used to treat certain conditions?

How can we 'delete' bad memories from our brain?

Which part of the brain allows some people to have a "photographic" memory?



Are there differences in the brain scans of people with and without mental health issues?

Why do some people recover from locked-in syndrome and others don't?

What makes someone a psychopath?

Why are pain and hunger controlled by the same region of the brain – is that why we get 'hangry'?

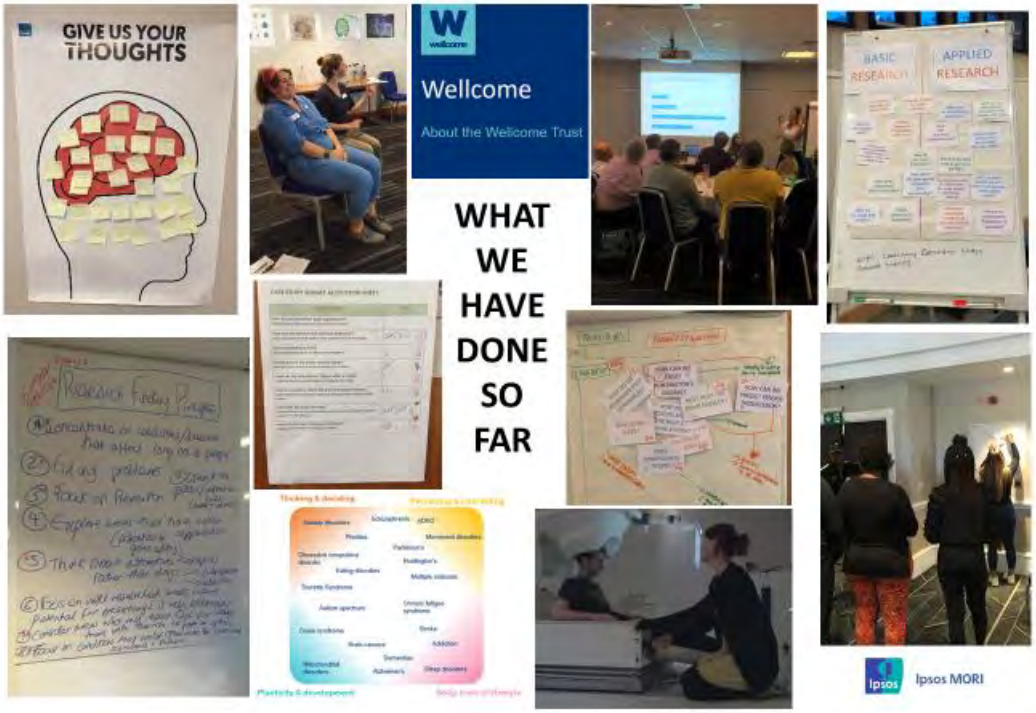
What makes someone right or lefthanded?

What causes Tourette's syndrome?

What causes obsessive compulsive disorder (OCD)?

Why do we make the decisions we make?

Appendix 1.9: Public engagement reflection and exercise



Thinking about public engagement in Neuroscience and Mental Health

List of possible engagement activities:

- **Science festival** (exhibitions and talks)
- **Documentary** (films or series that explore mental health and people's personal experiences e.g. Don't Call Me Crazy, The Horse Boy)
- **Game** (video game or board game)
- **Public dialogue** (group discussion with an open exchange of information and ideas)
- **Museum or exhibition** (that display historical progression of science and mental health e.g. Bethlem Royal Hospital Museum, The Royal Pharmaceutical Society Museum)

- o**Theatre performance** (a show that explores an area of science or research)
- o**Pop up exhibition** (temporary display in a public space e.g. shopping centre)
- o**Survey** (to gather public opinion on a topic)

- **Citizen science** (e.g. game or app or tools for people to input data or carry out their own science experiments)

- **Social media** (engaging the community through sharing ideas and thoughts)
- **Research interest group** (group of members of public with interest in furthering a research area)

Pick one area of research you would like to engage with and think of the following:

- **who** you want to engage, **how** you want to engage them
- at **which points** you would want to engage the audience (at the idea generation stage, proposal stage, initial research, intermediate research, final research, and/or afterwards to tell them about the findings)
- **who, or which groups**, you would want to engage and **why** (for instance, school children, patient groups, community groups, the general public, harder to reach groups, etc)
- the **benefits and drawbacks** of different techniques

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Report authors:

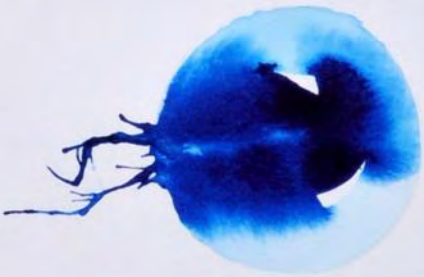
Michelle Mackie
Camille Aznar
Lydia Clark

For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos-mori.com
http://twitter.com/IpsosMORI



About Ipsos MORI's Social Research Institute

The Social Research Institute works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methods and communications expertise, helps ensure that our research makes a difference for decision makers and communities.