From our brain to the world: views on the future of neural interfaces

A public dialogue research programme conducted on behalf of the Royal Society

Findings Report



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Preface

This report has been prepared by Hopkins Van Mil: Creating Connections Ltd. It was commissioned by the Royal Society.

Neural interfaces (NIs) are devices that interact with the nervous system of an individual. Used in medical settings, these devices have existed for decades to help restore motor, sensory and other neural functions. With fundamental developments in neuroscience combined with rapid improvements in areas such as miniaturisation of components and internet enabled technologies, there is now greater potential for NIs to be used in more consumer focussed applications, for example in the fields of robotics and gaming. Work is being conducted on NIs which have the potential to improve human cognition, let us interface seamlessly with technology and compete with developments in artificial intelligence.

Such fast-moving developments are accompanied by questions of ethics, governance, feasibility and cost. The Royal Society's interest in this field is in part to consider the issues which need to be addressed if systems are to be in place to approve and regulate these emerging technologies. This study feeds into the evidence base which informs the Royal Society's engagement with policymakers, industry and the research community in the UK and internationally.

The Neural Interfaces Public Dialogue was designed and delivered by **Hopkins Van Mil (HVM).** HVM facilitates engagement so that voices are heard, learning is shared, and understanding achieved. In practice this means finding the process by which people can explore their hopes, fears, challenges and aspirations for the future. HVM's work enables stakeholders, technical specialists, and a diversity of publics to work together as equals to make actionable, better informed, and powerful decisions.

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1.1 Scope of the research

The public dialogue and special interest fieldwork (referred to in this report collectively as the public dialogue) were designed and delivered by HVM and managed by the Royal Society's Marketing and Public Engagement and Emerging Technologies and Futures teams. This research sits within the Royal Society's wider programme on Neural Interface technologies, involving a working group of scientists, academics and industry involved in the development of NIs. The Royal Society's Perspective on the future of neural interfaces will be published alongside this public dialogue findings report. The purpose of the engagement programme was to understand public opinion on the field of neural interfaces, how it may develop in the future and to co-create realistic visions for the future of NIs, enabling dialogue between scientists and diverse publics, shaping the development of the technologies in mutually desirable directions.

The expected outcome from the public dialogue is that the Royal Society will have gained an indepth understanding of the views of a variety of publics on neural interfaces and gathered input to inform early debate around future uses of these significant emerging technologies.

1.2 Participant recruitment

1.2.1 Public dialogue recruitment

Recruitment for the dialogue was conducted through HVM's fieldwork team against a detailed specification and screener. 9 participants were recruited for a pilot workshop in which selected materials and process activities from both dialogue rounds were tested. The findings from this workshop are not included in this report. On average, 24 people were recruited and retained for both dialogue rounds in Sheffield, Glasgow and



London, a total of 73 participants within the dialogue. 100% of the population sample was drawn from a broadly representative demographic of society. Within that, a third of the sample self-identified as early adopters of new technologies, a third as followers, only adopting new technologies when advocated by friends and/ or tested by others, and a third as resistant to, or late adopters of new technologies. This was to ensure the dialogue was an inclusive process encompassing a wide range of views on a significant area of new technologies.

The recruitment for the main dialogue workshops and the pilot was conducted through a network of fieldworkers and a panel approach, the combination of which enabled the team to meet the recruitment criteria, including quotas for each demographic. The approach was tailored to the selected location before implementation so that it broadly mirrored the demographic for the population in that area as described in the 2011 census. Participants who regularly attend focus groups or market research programmes were excluded. HVM aims not to recruit friendship pairs or to have snowball recruitment (where one participant invites another). We did not recruit those working or associated with the field of neuroscience in the study sample. These exclusions were to ensure that those with a significant experience of NIs could not unconsciously or consciously influence the group view, and/or find themselves becoming the voice of authority on the subject by other, less knowledgeable participants. However, it was important to the study that the views of people with this experience informed HVM's findings. HVM therefore held parallel discussions with gamers, people affected by Parkinson's disease and cochlear implant users (see 1.2.2).

HVM follows the Market Research Society Guidelines for qualitative research and the Economic and Social Research Council's Framework for Research Ethics (2015). As such we pay incentives for participants involved in dialogue sessions as a recognition of their time, whilst not compromising the principle of freely given and fully informed consent. In this case we offered an incentive payment of £160 for attendance at both sessions. To aid participant retention, £60 of the incentive was paid at the end of round 1 with the remainder paid at the end of round 2.

1.2.2 Special interest group recruitment

An important part of the process was to speak to those who may have a greater experience of NIs due to their lived experience as patients or through their leisure activities. People affected by Parkinson's disease were recruited via Parkinson's UK and their participant recruitment assessment process. This resulted in discussions with the 25 members present at the February meeting of the Parkinson's UK: Kensington and Chelsea support group and a Skype conference call with 6 members of a national research group. Cochlear implant users were contacted via a number of local support groups. As the Home Counties Cochlear Implant Group were meeting for their regular social in London within the research timescale, they invited HVM to join enabling two of HVM's senior researchers to interview 12 of the members present. 83 gamers were recruited directly by HVM as part of their attendance at the Pocket Gamer Connects exhibition and trade fair held in London from 21-22 January 2019.

1.3 Methodology

The dialogue design was informed by desk research drawing on the findings from a series of workshops involving the Royal Society's Perspectives Working Group. During these workshops, invasive and non-invasive medical and non-medical applications were discussed in their current form and in future 'moon-shot' long-term applications. In addition, HVM interviewed 6 members of the Working Group. We did this to gain their insight into the opportunities and risks in relation to the long-term development of NIs and to understand their aspirations for the public dialogue. These elements, together with discussions with the Royal Society, formed the basis of HVM's process plans for each of the dialogue rounds. The same process plan was used in each location to allow for a consistent analysis of the findings across each of the three locations.

A two-round process is a fundamental element of a deliberative public dialogue. It allows participants, the facilitation and project teams' time to reflect on what is being said and work flexibly in response to that. It encourages participants to think beyond their first thoughts. Participants experience a variety of evidence-based stimuli to help them engage in the subject of NIs with the depth of thinking so important to a subject rich in technological, ethical, social and regulatory complexities.

1.3.1 Dialogue materials

Participants were divided into three groups of 7-10 participants in each location, ensuring a balance of demographics and interest in new technologies (see 1.2). Each of these small groups was supported by a dedicated senior HVM facilitator. They remained with the same group for each round and worked with the same stimulus materials.

Round 1 Materials:

- An introductory presentation explaining the purpose of the dialogue and defining neural interfaces as 'A wide range of technologies which link the brain, spinal cord and/ or peripheral nerves to external devices to record and/ or stimulate activity', as well as describing their origins
- A jargon buster was included in the participant pack explaining key terms that might come across during the dialogue this was also displayed on the workshop wall
- A set of video clips taken from a range of sources showing case studies of current developments in medical¹ and non-medical applications² such as:
 - o Multi-channel cochlear implants
 - \circ $\,$ Deep brain stimulation treatment for Parkinson's disease
 - o Neurorehabilitation after a spinal cord injury
 - o Implants to restore communication function
 - o Mollii suit treating motor rehabilitation
 - \circ Understanding action potential through brain waves e.g. for use in gaming and robotics
 - o EEG headsets to improve human reactions whilst driving
 - o Biohacking to demonstrate that anyone can experiment with NIs



Round 2 Materials: an introductory presentation on the future of NIs was prepared and delivered by HVM. This emphasised the importance of participants' input through the dialogue given the amount that is unknown about the potentially dramatic and extensive changes that neural interfaces could bring about in society. Video clips from a range of sources³ was used to provide examples of NIs on the near horizon but not in mainstream use. These

included for neurorehabilitation, but also the potential for NIs to enable humans to compete with artificial intelligence and to think about the limitations of our human bodies compared to the potential of the human brain. These clips were supplemented by a set of near future NI examples which included developments in:

- Education
- Obesity management
- Defence
- Creativity
- Miniature electronic devices to treat chronic disease (electroceuticals)
- Communication
- Neurorehabilitation/ motor skills
- Gaming
- Mental health
- Cognitive enhancement

³ <u>The Economist</u>, <u>CtlLabs</u>, <u>BBC</u> Where stories, ideas and views matter www.hopkinsvanmil.co.uk



¹ Medical: <u>University of Newcastle</u>, <u>World Science Festival</u>, <u>Stamford University</u>, <u>BBC: Horizons</u>, <u>Stora DesignPreset</u> ² Non-medical: <u>CNBC/ CtrlLabs</u>, <u>Nissan</u>, <u>Modern Rogue</u>

Up on the wall throughout the workshop was a set of questions asked by participants during round 1 and the answers to them prepared by the Royal Society. They worked together with the jargon buster to further stimulate discussion.

1.3.2 Recording the workshop discussions

It is important that the discussions are recorded effectively so that participants' discussions can be transcribed and used for data collation and analysis. HVM uses three main recording methods:

- Audio recording of each small group and the plenary sessions these recordings are transcribed after each workshop
- Flip chart recording by the facilitator who notes the key points made and themes arising
- Post-it notes used by participants to record thoughts and headline points in their own words these are transcribed as part of the flip chart transcription process.

At the end of round 1 participants were asked to spend time in the weeks before the next workshop interviewing friends and family members using a template to record their reactions to NIs in medical and non-medical contexts. The completed forms were returned at the beginning of round 2 and

transcribed for analysis. Photographs were also taken of two sets of visuals created by participants. The first set was again completed between rounds 1 and 2 depicting a future NI application. The second was part of the end of round 2, in which participants were asked to work together to create an optimistic and realistic vision for the future of society with NIs. These were created on A2 sheets and integrated into NVivo analysis together with all other data.



1.3.3 Round 1 summary

The round 1 workshops were held in the evening, beginning at 5.45pm and ending by 9.00pm. The workshops kicked off with warm-up discussions, in which participants worked in their small groups and discussed their responses to any new technologies they could think of. This first workshop set out to put NIs in context, explain current developments and give a space for participants to ask questions about medical and then non-medical applications. As part of this process, groups were asked to consider their first reactions to NIs and to think about the criteria by which they would decide what was a desirable or an undesirable use for NIs.

1.3.4 Round 2 summary

Full-day round 2 workshops began at 10am and ended at 4pm, with participants reporting back on their interviews with friends and family members. They also shared their future application visuals which were put on the wall to continue to stimulate discussion. During the session participants worked on a PESTLE exercise to consider the political, economic, social, technological, legislative and economic drivers which could push the future development of NIs. They were supported by their facilitator, and expert witnesses were on hand to answer questions and provide constructive comments.

This was followed up with an activity to consider the incentives, safeguards and conditions that should be put in place, given the points they had made on what is driving developments. These were prioritised and then shared in a plenary session.

The afternoon of the workshops began with the HVM facilitation team giving examples of the significant changes brought about by equally significant technological developments such as the industrial revolution. This came with an exhortation to participants to *think big* and focus on the changes for society rather than the impact of individual applications. The rest of the workshop involved the creation of a vision for society in which neural interfaces are an integrated part. This was done incrementally, using the examples of near horizon applications, via:

- 1. A discussion of the changes that participants thought would occur in society as a result of the ongoing development of Nis, and
- 2. Consideration on a timescale of now to 2100 of when these changes are likely to occur



Each table worked in two smaller groups to create the visions. They were discussed with the expert witnesses in a final plenary discussion. The dialogue ended in each location with a clear explanation of the next steps in terms of converting all the fascinating and deeply reflective responses to NIs into a findings report.

1.4 Recording, analysis and reporting

A vast array of written and visual materials resulted from the two-round process in three locations, plus the special interest groups fieldwork. The recording process is set out in 1.3.2. HVM uses framework analysis as a robust process for large qualitative data sets. Transcription is the starting point, with constant re-reading of the data to ensure team familiarisation. The data reduction stage involves data cleaning and iterative labelling so that early codes emerge. We use NVivo software to facilitate this process, which enables the coding of visual and audio material, as well as text. This begins with data from each of the workshop locations before aggregating across all data sets so that we can compare location specific with national findings.

The initial coding framework is developed and reviewed in a team analysis workshop, where HVM discuss patterns and themes, compare our perspectives, identify relationships between data categories, and test the validity of the codes, ensuring they are exhaustive for the purposes of the study. The NVivo coding framework is used as the principal tool for analysis with data searched for statements that fit into the conceptual categories. Coding and analysis was conducted iteratively across the programme beginning from the first data collection so that emerging findings were reported on as headline findings after rounds 1 and 2 and used to inform the next stage of the programme. HVM team analysis meetings were held to agree each analysis round, followed by opportunities for the Royal Society Project Team to see and comment on the headline findings. The report was written from March to April 2019, presented in draft form to the Royal Society with opportunities for comment and review with a final report being submitted in May 2019.

1.4.1 Note on the report

Throughout this report participants' own words and images have been used. The text in grey boxes are summary transcriptions of participants' reporting of the interviews with friends and family they conducted between rounds 1 and 2 of the public dialogue. They also incorporate longer verbatim quotations from discussions at the workshops; with cochlear implant users, with members of Parkinson's UK, and from gamers attending Pocket Gamer Connects as vox pops, giving a fuller picture of participant responses to NIs in their own words. Where necessary, names have been changed to protect the anonymity of participants and their friends and family.

2. Range of reactions to neural interfaces

Chapter 2 summary

In this chapter we provide a brief overview of the range of reactions to NIs expressed by workshop participants, gamers, Cochlear Implant users and people with Parkinson's Disease. Concerns and questions about medical and non-medical NIs are explored in more depth in Chapters: 3. Participant considerations for acceptable use; 5. Implications for society; and 6. What does it mean for humanity?

Reactions to examples of medical NIs were strongly positive. Most were unaware of technologies such as deep brain stimulation for Parkinson's Disease and were impressed and fascinated by their effects. Non-medical NIs tended to be directly compared to those for medical use and therefore judged as more frivolous at first. However, as NIs and examples were discussed during the two workshops, reactions evolved and participants could ascribe some benefits to non-medical NIs, such as increasing people's ability to learn and that non-medical technological developments had the potential to drive developments in medical NIs. However, there remained a note of caution about how humans and non-medical NIs interact.

Medical NIs

Excitement

Wow! Fascinating Positive Liberating Enhancing independence Benefits outweigh risks

Concerns

Clunky devices Battery life Side effects Lack of precision in surgery Who has access?

Non-medical NIs

Concerns

Where will this lead us? Unintended (mental) health impacts Brain hacking Discouraged social activity

Excitement

Evolution Developments beneficial to medical sector

Enhance knowledge and communication

2.1 Reactions to medical neural interfaces

Wow! was an often-heard exclamation of participants and those they interviewed for their homework when they saw examples of medical NIs. The medical NI examples with the highest 'wow factor' were the videos that showed Paralympian Jennifer French using a cortical implant to help her stand and walk from her wheelchair and a man with Parkinson's being able to control his tremors with deep brain stimulation. These examples showed an instant transition from disability to some form of restored movement and control. Participants, such as this one from Sheffield, talked about this immediate benefit and were even more impressed that it was achieved with seemingly few or no side effects.

My friend Miranda, I showed the Parkinson's video to her and she was like, 'Oh my God, what is happening here?' It felt super forward... It looked like magic to her. | Sheffield

The 'wow factor' was also generated because most participants were unaware that technology to stop tremors, to help people walk or to control a cursor with the thoughts in your head actually existed.

Both felt that in a medical setting it was fantastic. My boyfriend was like, 'Wow, you can give someone's life back'. He had no idea about the medical applications and was blown away. | London

The potential for NIs to dramatically improve lives in a wide range of ways also earned this technology the admiration of participants and the family/friends they spoke to. They could see opportunities for a wide range of physical and mental health issues to be improved and that this would be beneficial both for the patients and their families.

Participants with cochlear implants also talked about the 'wow factor' they experienced when they first used the device and the impact it has had on how they live their lives. They talked of the transformative effect of feeling part of the world again and being able to interact with people, beyond just their closest family. That this has been achieved with next to no side-effects added to their high level of satisfaction with their NI.

It's opened up the world for us. | Cochlear Implant User Group

A cochlear implant is fantastic. It is the first thing I reach for in the morning and I panic if my processor gets lost. You rely on it and are lost without it. | Cochlear Implant User Group mid-40s. She was fascinated by the whole thing. She cares for my grandma and with medical purposes it would be life-changing. She wasn't too sure what kind of things, but she was excited to see what comes up and she felt quite positive that it'll help. Sheffield

I spoke to mum. She's in her

2.1.1 Views on benefits of medical NIs

In discussing their first reactions to examples of medical NIs in round 1 and the examples shared in round 2, participants were quickly able to identify a range of benefits, which are summarised in figure 1.



Figure 1: Initial views on benefits of medical NIs

Inspired by the videos they had seen in round 1 about restoring physical abilities, participants' ongoing reactions to NIs tended to emphasise the freedom that they could offer to people with mobility and sensory disabilities. Whether being able to communicate via an implant or EEG, being able to walk with the help of a cortical implant, or the potential for hearing or sight to be restored, participants saw it as an opportunity to free people from a limited life and from dependency on others. They also saw NIs as offering a chance for a more equal society because disabilities can be associated with unemployment and other physical and mental issues.

This is going to be life-changing for people who struggle and people who have disabilities. | Sheffield

Anything to help the future generations overcome disability is a good thing. | Cochlear Implant User Group

The potential for medical NIs to provide targeted treatment, as highlighted particularly in the Electroceutical example, received very positive reactions from participants. They liked the idea of a treatment that doesn't have to be absorbed by the whole body. It could minutely target the health problem and leave the rest of your body free from any side-effects.

I think the target in the problem area rather than having medicine that works all over. The side effect of them would be better for your body, so your body doesn't need to filter more unnecessary things. | Glasgow

From the first moment of sharing medical examples of NIs, participants were curious about their applicability to mental health issues. If successful NIs for mental health could be developed, participants saw the potential for wide-ranging, positive impacts on society such as reductions in levels of crime and homelessness.

In terms of both physical and mental health, some participants saw the opportunity for society to be less reliant on 'Big Pharma'. If conditions could be treated in a targeted way, as described above, through an NI, then medical interventions would be more precise, and people wouldn't be on a cocktail of medications with associated side-effects.

Some participants saw the application of NIs solving some of the world's most intractable medical problems as a hugely positive contribution to the narrative around technology in general. They thought that NIs that could restore movement to those who are paralysed or sight to those who are

blind could help to rebalance the tech narrative that to date has been dominated by large social media companies and their use of data and artificial intelligence to influence our behaviour,

It develops a positive narrative for technology. Not every tech gets a bad record but more from the media it gets quite negative.' | London

Whilst participants were quick to express their enthusiasm for medical NIs, questions and concerns were raised as they thought about their implications for individuals and society. Some expressed concern about the risk of surgical techniques to implant them, and their hackability once the NIs are operating. Hacking an implanted NI was seen as far more concerning than an external NI because participants worried that they would be hard to re-set.

When observing the man with Parkinson's switching on his DBS device and instantly alleviating his tremors, some participants, after their 'wows', wondered what the long-term effect of using this treatment would be. Whilst they did not believe its use should be limited, they were keen for scientists and clinicians to be thorough in their ongoing evaluation of NI treatments such as these, to avoid revelations of negative side effects in years to come.

The only negative she saw was if it could harm them in the long run if you had the Parkinson's one for so long, what are the side effects after too long? | London

Alongside their sense of wonder about NIs, many participants instantly raised an expectation that they would be regulated in a way that made them acceptable to society as a whole and would make it difficult for them to be misused or do more harm than good. Later discussions on regulation, as covered in Chapter 3, give greater insight into how regulation might operate, but the expectation that it be in place was there right from the start of the discussions.

We all thought it was fantastic, didn't know it existed. Then we became slightly suspicious of how it could be misused, but as long as it's regulated it's fine and it's great if you have an injury and rehabilitation. | London

Concerns and questions about medical NIs are explored in more depth in Chapters: 3. Participant considerations for acceptability; 5. Implications for society; and 6. What does it mean for humanity?

2.2 Reactions to non-medical neural interfaces

Non-medical NI examples were shared with participants after the medical examples. Naturally, at first, many participants drew comparisons between them and often found non-medical examples to be frivolous, worrying or both. This reaction therefore prompted more immediate questions and concerns than medical NIs. They ranged from observations that non-medical NIs might potentially discourage social interaction; lead to a divided society inhibited by those using NIs versus 'luddites'; and may have a negative impact on physical and mental health.

After watching videos such as CTRL-Lab's enhanced motor skills example, participants tended to ask: what problem is this trying to solve and where will this technology take us? Unlike the medical NIs which were addressing a clear problem, participants found it harder to see concrete Where stories, ideas and views matter [13] www.hopkinsvanmil.co.uk benefits in a computer being able to read your movement intentions and control a cursor or robotic arm. These developments didn't seem to be addressing critical issues, instead it was about *a want, rather than a need*.

Participants recognised that NIs can make life so much easier but worried that they might encourage laziness and the risk of humans leading more sedentary lives. As a small group in Sheffield reported back to the plenary session in round 1:

Our first reactions, we felt that they could make life very convenient. [...] You could use it to take care of routine things that you don't want to do, just think, and your robot hoover will hoover. That will free you up to do things you want to do. It might make people lazier though, less active, less creative, and that might have an effect on their health, more sedentary lives. | Sheffield

There was a view that the laziness could extend to mental laziness with potential dumbing down of mental capacities as a consequence. This affected the initial views on the desirability of non-medical NIs to some.

It could make you mentally lazy. You could have something that would be making sure your doors were locked. I don't want to be mentally lazy. I want everything, mentally, to stimulate. | Sheffield

NIs for non-medical purposes rings an alarm bell inside of me. It all sounds quite innocent, fun and adventurous, but I feel from experience of the past few years, that the technology will definitely fall into the wrong hands and who knows what they will use the technology for? I am very concerned about NIs being used for nonmedical purposes and feel like we are opening a Pandora's Box. It's a shame, because the idea is a good one. Glasgow

NIs for non-medical purposes is a brilliant way of getting the technology out there, in the public domain, which in turn will bring in the finances to bring the cost of the medical side down. I particularly like the idea of the driverless car and the idea that the car will drive itself based on our thoughts and intentions. As someone who enjoys online gaming, I also like the idea that paralysed kids (and adults) will be able to join in and play video games just using their thought process! I look forward to this new technology! London

In comparison to some of the medical NIs, some of the non-medical examples seemed to have 'slicker' design features and more cutting-edge technology. Participants felt that developments created for non-medical NIs could cross over and help improve medical applications.

NIs are useful in many ways, it can be used as a distraction device for conditions, such as pain or psychological problem, as a part of medical therapy. It can also be used as a learning device, improve and synchronizing how the brain receives and learn information through interactive formats. | Pocket Gamer Connects

The idea of connecting to an NI to improve your health or enhance your life experience was very exciting to some research participants and interviewees. They saw the opportunity to go beyond their current body's capabilities or the current technology of screens and consoles, to being completely immersed in a different world.

I spoke to one of my housemates in his early 20s. He was very enthusiastic about all of it, especially both medical and recreational uses. Direct quote, 'Turn me into a cyborg.' | Sheffield

Concerns and questions about non-medical NIs are all explored in more depth in Chapters: 3. Participant considerations for acceptability; 5: Implications for society; and 6. What does it mean for humanity?

3. Participant considerations on acceptable use

Chapter 3 summary In this chapter we provide an overview of the way research participants made decisions on the acceptability of NIs, including the considerations made to distinguish between enhancement and non-enhancement applications of NIs and the levels of invasiveness in various contexts. The following summarises their views.					
Aesthetics and usability Internal NIs					
Convenience and comfort for the user	Miniaturisation				
Ease and effectiveness of operation	Comfort and mobility				
Biodegradable materials	Safety of the device				
Trade-off between aesthetics and quality of life acceptable	Enhancing quality of life or saving life				
Restoring quality of life	Enhancing quality of life				
Extended life expectancy	Balancing individual and societal benefits				
Reduced pain	Equity of access				
Improved ability to communicate	Not used to exercise unwanted control				
Increased independence	Careful management of health impacts				
Safety and impact on health	Control, transparency and choice				
Rigorous testing, ideally by academic researchers	Personal choice; proactively opting into the use of NIs				
Tracking health impact over time	No imposed behavioural manipulation				
Holistic testing, in and outside the lab	Option to turn NI on and off				
Trials involving wide range of people	Legislation to avoid corporate monopolies				

Equity of access Ethical framework	
Base level of NIs widely available on NHS	Parameters of use
Priority to high incidence conditions	Open standars and transparency of information
Wide range of people involved in trials	Safety of the devices
Affordability non-medical devices	Data protection assurances

3.1 Equity of access

NIs to mitigate paralysis, Parkinson's and MS symptoms and hearing loss were all seen as impressive medical breakthroughs by participants in the dialogue, the people they interviewed between round 1 and round 2 and the patient groups consulted. An important condition for acceptability of NIs is an expectation that everything should be done to ensure equity of access to the advances in medical science.

3.1.1 Equity of access – considerations on criteria for acceptability

One of the first considerations made by research participants in relation to medical NIs was *Who gets to have it and who makes that decision?*

Across the locations, participants agreed that a desirable future is a future where NIs are available to all who have a medical need for it. Should further prioritisation be needed due to a lack of resources, the severity of a condition and level of discomfort and pain were mentioned as supporting criteria. As a participant in Glasgow said, having watched the video of Paralympian Jennifer French,

The lady in the chair is paralysed from the neck down, it's people that are actually in need of it, rather than you've got one twitchy finger and you think that you should be in a study. You should be at a certain level before you are medically selected. | Glasgow

Out of concern for a deepening divide between what was called the *Have's and the Have nots,* participants said that a desirable future for NIs is a future where the applications are widely available on the NHS. As a participant in Glasgow said,

If it's the NHS, it's quite egalitarian. Everyone gets it. If you go to hospital, it's probably the most classless area. No point having it if it's not affordable for the masses. | Glasgow

And someone in London,

Would the Mollii Suit rise or decrease in cost over the years? If it rises, can a strapped NHS afford to buy them? It's relevant because if you can't use it, it is science fiction. | London

Many expressed concerns about what was called the current *NHS postcode lottery* which according to participants determines whether a particular drug or treatment is available depending on where in the UK patients live.

My friend acknowledged what it could do for someone with Parkinson's, but she was sceptical it would be available on the NHS and how widespread it would become. She thinks it would be for people who could afford to have it. | Sheffield

All research participants acknowledged that NIs for medical applications have the potential to bring unprecedented benefits to users. However, the point was made that inequality of access and giving people false hope will temper patients' wellbeing.

It gives people a lot of hope for the future but only if it means it's available to wider society in terms of cost. You don't want to think, 'There's going to be this thing that is going to completely transform my life,' and then realise, 'I'm never going to be able to afford that'. | Sheffield

If treatments are not being made available on the NHS, participants fear the divide between rich and poor will widen further.

Participants also felt that it is important that a wide range of people (age, gender, ability, ethnicity, faith) have access to NI trials. Some shared a belief that only patients with access to private health care are eligible for clinical trials, which they felt is not right.

Base level of medical NIs widely available on NHS Priority for high incidence conditions Access to trials to wide range of people

Affordability nonmedical NIs

Figure 2. Equity of access – considerations on criteria for acceptability

Some participants brainstormed what safeguards need to be in place to achieve equity of access to NIs. To avoid a society where, in the words of a group in Glasgow, the *survival of the fittest* prevails, participants discussed that having a base level of medical NIs that is widely available on the NHS is essential when there is a clear medical need.

If it's something necessary, there has to be a base level of NI that everybody gets. For right now, not everybody has the same house but we have council housing for people who can't afford housing. That's the base level for housing. | Glasgow

This raised bigger questions about which treatments should take priority over others when funding is limited. There was a view that in terms of equity of access, it is important to prioritise medical conditions with the highest incidence.

I think there's a choice between a low hanging fruit and the really extreme stuff. I don't know whether hearing is the easy one to go for, but if you could get huge numbers of people through it and get major benefit that way. I think there is sometimes the attraction of taking the really tough case as opposed to the one that would benefit the most. London

Across all locations and research groups participants mentioned regulation as the first safeguard to ensure equity of access.

I think that's where regulation steps in, to ensure everyone has a fair chance of accessing it. | Glasgow

This is explored further in section 3.8.

3.2 Aesthetics and usability

Having watched the case study films on both medical and non-medical NIs most participant groups discussed aesthetics and usability as considerations for the acceptability of NIs. Their views are summarised in figure 3.



Figure 3: Aesthetics and usability – considerations on criteria for acceptability

Many comments focussed on the design of the interfaces with dialogue participants in particular mentioning the size and shape of the medical devices, which in the eyes of many seemed *clunky*, *basic and immature*.

They wondered how much collaboration there is between researchers and graphic artists to optimise the design and navigation of devices to improve the ease of operation and the way they look.

To some the look and feel of the technology seemed out of touch with the current technological aesthetics and those we have been exposed to for example in sci-fi films.

It's not just about how big or small it is. It's whatever we see in technology nowadays looks so much more well refined. It's pleasing to your eyes. | Glasgow

I put down 'lag', in terms of the technology seems to be immature. We were talking about what our expectations are, as opposed to what the reality is, based on movies and whatever else. It seems more basic than perhaps we would have expected. | Glasgow

Respondents in the gaming community emphasised that to them ease and effectiveness of operation is an essential criterion for the use of EEG sets for gaming. As someone said,

Traditional controllers do a phenomenal job of simplifying complex actions - for instance, fighting or parkour - that NIs and other immersive technologies would have to improve upon to really change how people interact with games. | Pocket Gamer Connects

In general, there was a sense that in a desirable future for NIs, the devices are effectively designed to be as convenient as possible.

A driving force is not only to produce the neural interface but to make it better, more efficient for comfort, for use both for medical and non-medical purposes. Smaller and more compact, the same way smartphones started out bulky and are now small and light weight. | London

There was a general expectation though, that this will evolve, and comparisons were made with other technologies, including for example VCR recorders.

It's a bit like an old VCR recorder. Back in the day that's all you had to watch videos, but now you've got Netflix, so you just know technology is going to change. | London

Participants recognised that what matters most is how comfortable NIs are for the users, recognising that some patient groups are not necessarily helped by a sleek design.

With the overarching expectation that NIs offer opportunities for an improved quality of life they acknowledged that they would make a trade-off between aesthetics and the impact of an NI on someone's quality of life. In reaction to the video of Paralympian Jennifer French a participant in London said,



Until you're there, it's clunky, yourself might go, 'I'm happy with a pack, it means I can sit up. [...] Her quality of life has been considerably improved from that. | London

And participants in Glasgow,

We weighed up the trade-off between making a mind-blowing, positive difference to people's lives which we thought outweighed the clunkiness of the design. | Glasgow

A small number of participants mentioned that the use of biodegradable and environmentally friendly materials for the production of NIs is a must in a desirable future for NIs.

How environmentally friendly are some of the NI products? On a long-term basis [...] I think that's important. Materials, batteries, plastic things, it's something that's very big now. | Sheffield

3.3 Internal versus external devices

When asked for their preferences regarding internal and external NIs, dialogue participants and patient groups echoed some of the reflections on aesthetics and usability described in section 3.2.

Broadly speaking, both groups shared similar views about the benefits and disadvantages of invasive/ non-invasive NIs, a summary of which is given in figure 4.

Most research participants saw reversibility as a benefit of external devices and felt that internal NIs are a bigger commitment. Their perception was that there are no repercussions of reversing an external device and that people can carry on living as they were previously.

External NIs

Smaller commitment: reversability Lower risk: of side effects, infections, hacking Potentially stigmatising

Internal NIs

itself

Bigger commitment: harder to remove Higher/ unknown risk: of surgery, rejection, error Removing disability stigma More convenient: operating

Figure 4: Views on advantages and disadvantages of external and internal devices

It's reversible. If you have a side-effect, you can stop using it and try something else. If you find that after you've had an electrode implanted in your head, you're still going to have it there. You can turn it off, but it's a bigger commitment. Sheffield

External devices were generally perceived as carrying lower risk than internal devices, with participants expressing concerns about side-effects, infections as a result of surgery and rejection by the body of the internal device. The unknown risks sparked concern as well as participants felt the fact that devices are connected to the brain or peripheral nervous system means there is less margin for error.

It could cause new problems and potentially change people who are using it. The tech might damage their spinal cords so they couldn't walk. | Glasgow

An audiologist in the Cochlear Implant User Group reported that people discussing the implant with her express fears around surgery, particularly about the fact that the implant procedure requires drilling into the skull/ bones,

It's in the brain! | Cochlear Implant User Group

These discussions showed that safety of the devices is an important criterion for the acceptability of NIs.

Safety, obviously the interfaces are going in your body, as such as identified there's an increase in risk there because of that. They need to be properly tested, there needs to be an extensive safety record and research to check and determine what the long-term effects are. | Glasgow

Removing the stigma of disability was seen as a benefit of internal devices, particularly by patient groups. Members of the Cochlear Implant User Group for example, discussed that although acceptance of visible disabilities has improved since the 2012 Paralympics, the appeal of internal NIs is strong because prejudice was still felt. Several participants in the Cochlear Implant User Group talked about the new development in cochlear implants which will be fully internal and controlled by a mobile phone. This was liked for taking away the stigma of an external hearing device.

3.3.1 Considerations on acceptability criteria for internal NIs

In the eyes of research participants, internal NIs are more convenient for the user due to the portability of the devices. There were split views on the desired level of user autonomy required for acceptability, with non-patients expressing concerns about not being able to control the device and patients emphasising the convenience of automated internal NIs.

In the Parkinson's UK group, patients shared their concerns about Deep Brain Stimulation (DBS) being operated by a remote control. Talking about a broadcast in which a patient was asked if he would show viewers what happened if he turned off his device one of them said,

It was a person who had PD and then he said he didn't mind it all. [...] It was turned off and he descended into a complete wreck. Then they turned it back on again and he was perfectly okay. If that can happen, why is there a switch? | Parkinson's UK Patient Group

In their view this makes a patient vulnerable to losing access to the neural interface. As someone said,

A very dangerous thing to carry around. You might leave it in your handbag or find your grandchild play with it. | Parkinson's UK Patient Group

Some patients worried about the responsibility that comes with a device they have to operate themselves. Instead of having to make decisions on the right setting for any given moment they prefer a device which automatically administers the right amount of electrical pulses.

The ideal solution is seen as something like DBS where you can put something in and not worry about it. You turn a switch and it works. You go to bed at night and turn it off. | Parkinson's UK User Group

Research participants said that the smaller an internal neural interface is the better, as surgery will therefore be less invasive.

Looking first of all at miniaturisation, just in terms of people can be scared of having things put inside them. The easier it is to do that the more people will want it, so adoption will be increased because it's less painful. | Glasgow

Some hoped that it will soon be possible to inject tiny biodegradable chips into the body that can be activated from the outside. Their expectation was that this makes the use of internal NIs reversible, which touches on another criterion that makes a future with NIs more acceptable in the eyes of most of the research participants.

If you decide that you do want to take part and later on down the line you don't want to be a part of it there are no repercussions and you can undo what was done and carry on living as you were previously. | London

However, despite the above considerations, quality of life and saving life were the overriding decision-making factors when research participants were asked for their preference between internal and external devices.

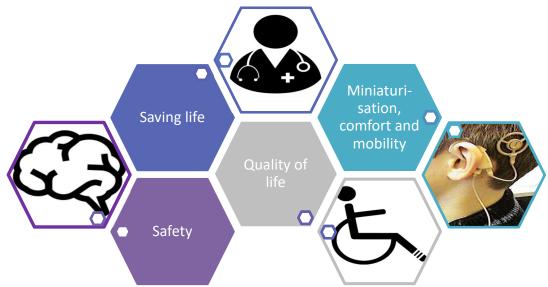


Figure 5: Internal neural interfaces – considerations on criteria for acceptability

Patients using an implant tended to be more open to internal NIs, saying that it has been a risk worth taking because of the enormous impact the internal NI has had on their quality of life. For example, a woman in the Cochlear Implant User Group spoke of being one of the very first in the country to have the surgery and said when she discussed it with the surgeon he tried to persuade her to wait until the application was more thoroughly tested. As she also experienced tinnitus, and was finding the symptoms of this intolerable she decided to go-ahead nevertheless.

I was at a crisis point, even though I had two small children, I felt I couldn't go on. I felt I had no choice, in fact I had nothing to lose. | Cochlear Implant User Group

The cochlear implant has not only improved her hearing, but in addition she doesn't experience tinnitus when she is wearing it which means her quality of life has improved dramatically.

A mental health nurse in London had seen some of her patients making similar trade-offs between risk and the potential to improve their quality of life,

I'm a mental health nurse, so I have seen a few of these first-hand, the results of what it can do for people. The quality of life is outstanding, how it can change somebody's life. As soon as a cochlear implant is switched on, it's immeasurable. | London

Some dialogue participants expressed the hope that applications will be developed which can be offered both as internal and external devices so that patients have a choice.

It should be made in both ways if that's the case, there should be an option where you can choose what best suits you. A lot of people don't like things internally, they're disturbed by that kind of thing. If there was an option, it would allow them to choose. | Sheffield

On balance, the research shows that views on invasive versus non-invasive NIs depend on the context and individual preference.

It comes down to the individual case. Maybe the internal has more effectiveness and therefore it's more necessary, so there's an element of convenience and an element of preference. | London

However, there was a strong sense that most people will embrace an invasive NI if it's a last resort to save life or significantly improve a patient's quality of life.

I don't like the idea about putting a device in my body, however if it was going to save my life I would. | London

3.4 Restoring quality of life

Restoring quality of life was seen as a key and often overriding decision making factor around the desirability of NIs for medical use. Overall there was a view that medical NIs offer opportunities to regain something that has been lost due to injury or a medical condition.



Figure 6: Restoring quality of life - considerations on criteria for acceptability

Across the research groups participants identified four criteria which in their view enable users of medical NIs to enjoy a quality of life that is typical for those who don't have a neurological condition or disability: a reduction in pain and suffering, an extended life expectancy, the ability to communicate or focus and an increased independence.

It's difficult for me to think of an undesirable use of neural interfaces. It's regaining a sense or something you've lost. | London

A reduction in pain and suffering and increasing someone's life expectancy were both seen as valid criteria for the use of medical NIs.

If it expands life, that's good, but if it helps the pain, even if it doesn't extend their life, that should also be through. | Sheffield

Across the research groups, participants recognised that medical NIs which restore a person's ability to communicate vastly improve an individual's quality of life as it reduces the social isolation that can be experienced as a result of a speech or hearing impairment.

This was confirmed by Cochlear Implant Users some of whom talked about how the device had made it possible to use a telephone; how it had improved their speech; and how the shift from the more cumbersome hearing aids to the more comfortable cochlear implants had improved their lives. They said the implant had *opened up the world* and reduced feelings of isolation.

Before I had the implant I would keep my group of people small. I became very isolated as my hearing worsened. | Cochlear Implant User Group

Even though non-medical NIs tended to be discussed more in the context of futures in which enhancing quality of life is acceptable (see section 3.5), some non-medical devices were referred to in discussions about restoring quality of life as well. Some respondents in the gaming community saw EEG headsets as an opportunity for an enhanced gaming experience as well as a way to restore communication.

It would improve communication with people who are less able, can't speak, or can't type. People who are paralysed or locked in, have some neurological disease which means they can't use their hands properly to text, or pick up a phone. | Pocket Gamer Connects

In the same way keyboard-less typing was seen as a non-medical NI that offers opportunities to restore the ability to communicate for those who have difficulty communicating using speech or hand movements. As someone in Sheffield said,

It will help with depression of people who are severely disabled and unable to participate in the real world to gain some sort of connection to the real and virtual world through mental communication. | Sheffield

Increased independence was the most cited element of a restored quality of life. Participants felt this is an important benefit of both medical and non-medical NIs as current community structures very rarely allow for sufficient informal support for those who are relying on others for their basic care.

Society has become so fragmented now. [...] This gives people a choice to potentially support themselves. | Glasgow

Someone in the gaming community said,

In general, it would make life for disabled people much easier if this were to be integrated into a smart home setting. It would make it easier for people to move around their own home environment if doors could be opened and closed with a thought, or machines would not need small buttons to be operated. | Pocket Gamer Connects

The link was made to how a more widespread use of medical NIs will reduce the need for carers and ultimately the cost to society of health and social care services (see section 5.2.2).

My first interviewee was Jenn, my companion, she's 55. She's interested in NI in medical applications, especially in aiding the repair of damage to the brain after serious head injury. That's because, as a survivor of a hit and run accident 25 years ago that hospitalised Jenn for seven months, she lives with issues such as walking and balancing disabilities, short-term memory and several other issues as a result of brain injury. She said that maybe NI is a solution to restore quality of life and not having to depend on care. London

If you can switch televisions on and off, you can do day-to-day things yourself again, it's given them their independence back. It's relieving the struggle of carers because apparently there aren't enough now. It relieves the NHS. | London

3.5 Enhancing quality of life

Using NIs to enhance quality of life by giving people new attributes and skills led to discussions about the implications this type of neural interface technology might have for humankind. A participant in Glasgow talked about a belief that science will always want to push the boundaries.

If it's a skill or an attribute that a person has never had, should we bestow it upon them because we can? [...] With this new technology, you might push the new norm to be ahead of what a normal person is born with. You're pushing boundaries, establishing a new baseline of human intelligence. | Glasgow

NIs to enhance quality of life beyond the recovery of lost physical and mental abilities were discussed in terms of:

- Convenience making life easier i.e. smart home applications;
- Improved capabilities and performance in sports and gaming; and
- Enhanced experience in entertainment and art.

3.5.1 Enhancing quality of life – acceptability criteria



Figure 7: Enhancing quality of life - considerations on criteria for acceptability

Participants said it has to be clear at all times what the benefit of pursuing life-enhancing NIs is, at individual and/or societal level. This might be more convenience for the user or increased investment in research and development which feeds into the development of medical NIs. One of the groups in Sheffield summarised this consideration as follows,

If you're going to develop a non-medical product, why? What does it give us that we didn't have before? Is it so that we can play Space Invaders with our mind? How big a benefit is that? For a customer, it might be more convenient to do one of those things. For a CEO of a tech company, it might be that it makes them more money. There might be other fringe benefits. That technology might be taken further by commercialising it. That can be handed back to the medical industry, and advance medical applications. | Sheffield

Enhancement of physical capabilities and performance was seen as a matter of societal choice, particularly in the context of sport, where currently drug use is not allowed. Views differed on its acceptability, with some participants saying it would diminish their admiration of the skill and hard work of sports people. Those that did foresee the greater use of NIs in sport generally agreed that an important condition is that everyone should have access to the devices.

If one person was using an enhancement, everyone would be using them. In some way, it would be fair. | Glasgow

This sentiment was echoed in the gaming community, where equity of access was mentioned as a criterion for the acceptability of NIs, out of concern for a two-tiered gaming community.

There was a substantial number of research participants who showed an interest in applications that would improve memory and concentration functions or offer help in switching off and falling asleep.

If you want to have better memory, eyesight, cognition and faster responses, than these things could help to trigger a super quality, an enhanced quality of life. | London

This type of neural interface was cautiously welcomed but sparked discussions about the implications for humanity (see chapter 6) and reiterated concerns about how this could potentially lead to a two-tiered society if there is no equity of access to the devices.

Quality of life enhancing NIs that feed unwanted information back to the user were a clear no-go area for most research participants. There was concern that this might lead to behaviour a user has not consented to, as opposed to behaviour change an individual voluntarily signed up to, e.g. an NI to stop excessive food consumption to avoid obesity.

Can it be used to control you to do something that you wouldn't choose to do? | Glasgow

A group of dialogue participants in Sheffield discussed that they felt it is acceptable for a neural interface to gather data to improve an individual's performance, as long as no one else but the individual decides how they are going to use the results.

There's a line. If you're gathering data to tell people to do things a different way, but if they're doing it themselves, that's okay. | Sheffield

Similar concerns were echoed in the gaming community. A number of respondents at the Pocket Gamer Connects show said that for experience-enhancing non-medical NIs, feedback of data or commands to the user is undesirable.

As long as the input is user to game and no feedback if fed back to the user via the neural interface without conscious processing of the information, I have no concerns beyond existing concerns. If we reach a stage where it's a two-way street, this has lots of damaging potential. | Pocket Gamer Connects

Participants were fairly positive about the use of non-medical NIs to enhance experiences in entertainment and creativity. One of the respondents at the Pocket Gamer Connects Show in London said,

Generally, the idea of thinking-to-action is extraordinarily appealing from a gaming perspective bringing users closer to the experience. | Pocket Gamer Connects

In a similar vein, participants in Glasgow discussed that a neural interface could bring artists closer to the source of their creativity (see section 4.3).

Some compared the use of NIs to enhance experiences to recreational drug use.

I think the position of NI within society, if it's used in a pleasurable aspect, or as a crutch in that sense, how is it different to recreational drugs? That comes back to the regulatory nature of it. Sheffield

There was agreement across the research segments that a clear criterion for the acceptability of experience-enhancing NIs is careful management of the impact of the NI on the user's health. This applies whether the devices are internal or external to the body, with concerns being expressed about the potential side effects of internal devices and the addictive nature of gaming.

I'm not concerned, but there needs to be considerations for safety for the player. What are, if any risks to health, in terms of the player becoming 'too' immersed and not focused on their surroundings and needs (food, drink sleep). | Pocket Gamer Connects

Participants also deliberated on the implications for humanity of a potential dependency on an enhanced quality of life. This is discussed further in section 6.3.

3.6 Safety and impact on health

The safety impacts of neural interface technologies on the user's physical and mental health was of paramount importance to all research participants. For most, this was particularly important for invasive NIs as they recognised that NIs are still in a developmental stage and that the long-term health effects are unknown. Concerns ranged from a fear of the NIs exploding in the body to the radiation the implants might emit.

3.6.1 Safety – considerations on criteria for acceptability

For research participants safety of NIs has to be proven through rigorous testing akin to drug trials. They said that trials should be open to and involve people of a range of ages and backgrounds, including those who are on the autistic spectrum or have other special needs. As a participant in Glasgow said,

If we were ever compelled to have these in the future, they would have to be properly tested, safe and have a proven record of not hurting or endangering life. | Glasgow

Rigorous testing, ideally by academic			
researchers			

Ö	Tracked over time
6	Holistic approach: physical, mental and emotional impacts
S	In and outside the lab
	Trials involving wide range of people

Figure 8: Safety - considerations on criteria for acceptability

The latter was felt to be important as evidence of the impact of NI use over time was seen as a decision-making factor. As a group in Sheffield said,

The research that's been done on the device. If they're saying, 'After five years, we're not sure,' it's the length of how long it has been deemed safe. | Sheffield

Some argued that testing has to be done in a holistic manner, measuring the physical, mental and emotional effects of NI use. In relation to the NI for education shown as a case study in round 2, where pupils wore headsets that reportedly read

their brainwaves and indicated if they were attentive or not, participants in Glasgow concluded,

Doing that within classroom environments in different areas throughout the UK. Not only testing that, but just see how the children themselves feel about it. Making sure that it's not just focussed on the technological side of it, but how are they behaving alongside this technology? Maybe track a whole group of kids from primary school into adulthood and see how they function in their personal lives, psychologically, their relationships, all the extraneous factors, and see how that relates to it in terms of developing it further. | Glasgow

Others argued that for them it would be important to have evidence that NIs are tested in and outside the lab, in the real-life context in which the technology will be used.

If you're trying something new, it has to be watertight. It has to be proven time and time again in loads of different settings. Take the military context for example. You may test something in the lab: 'Yes, this is great' and all of a sudden they're in Afghanistan. Is it safe to take it from a lab into a military setting? London

Across the locations, researchers based in academic institutions were most trusted to lead the development of safe NIs. Participants recognised the role pharmaceutical companies are likely to play but some said they were wary of profit motives pushing the devices on the market at the cost of safety. As a group in Sheffield said when presenting their vision for the future of NIs,

Trust through knowing with the fine print that these are university research based and academic scientists, [who are] not into massaging the data to get the results they want but rather dealing with concrete achievements as they actually stand. | Sheffield

And participants in Glasgow,

For the ideal side we wanted more university researchers being on the forefront investigating and researching neural interfaces versus pharmaceutical companies, which seems the realistic thing in our minds. | Glasgow

3.7 Control, transparency and choice

Considerations about loss of control were made in relation to data, undesirable uses of the technology, and having a choice on whether to use the technology or not.



Figure 9: Control, transparency and consent - considerations on criteria for acceptability

Participants raised concerns about *everything being tracked* in today's society and losing control over their data, particularly to companies. They discussed a desire for transparency about who is gathering the data and for what purpose, as well as about the pros and cons of the applications.

Most participants felt there is more caution required with NIs than with other technologies. There was a view that data derived from thought and brainwaves indicating intentions, are more personal than data generated by the use of devices such as smartphones or the use of social media. A summary of their views on what needs to be in place to make NIs acceptable is given at figure 9.

3.7.1 Control, transparency and choice – considerations on criteria for acceptability Across the research locations, participants talked about a fear of losing control over the data being collected by NIs produced by the commercial sector.

Once we become dependent on neural interfaces, if it's only owned by a couple of people, they have all the power. | Glasgow

Out of concern that a future world with NIs will be dominated by a handful of large corporations (see section 5.7) there was a sense that safeguards need to be in place which ensure the unlawfulness of corporate monopolies. A group in London said,

We also came up with a point to do with safeguarding other businesses but also safeguarding other people in terms of fines for the misuse of neural interfaces, so that a conglomerate of companies can't develop it to a point they can monopolise it. | London

All research groups pondered the extent to which NIs are vulnerable to hacking, which was seen as another element of losing control, with data potentially ending up *in the wrong hands*. A participant in Glasgow said, for example,

Could you hack someone's mind if everyone's so connected? If they're half-computer, then you're beholden to somebody who could control that computer. | Glasgow

My other friend, potential risks she identified for things like gaming applications was information gathering, obviously we all know about that from Facebook and every mobile app you put on your phone demands permission to access your camera, microphone and files on your computer. She was concerned about the data gathered by NIs could add new issues by almost reading your mind. Glasgow There was suspicion that the very nature of the technology implies that someone else may be able to control movement/ actions, which was seen as undesirable for fear of violent or commercial misuse.

If you can control all your limbs, broken down into simple electrical impulses, somebody could control my arm and make me stab somebody. Or if you could tap into somebody's desire centre you could just sell me stuff. | Glasgow

In all research groups, people expressed concern about employers being able to control workers, which was seen as undesirable as well.

If the technology is used to exploit and oppress in the public space, for instance in the workplace. They could be maliciously used to control employees and squeeze even more efficiency out of them. | Packet Gamers Connect

As described in section 3.5 imposed behavioural change is for most people an undesirable element of a future in which NIs become commonplace. A participant in Glasgow's reflections show that consent will have to be multi-layered to avoid the neural interface gaining control over an individual's actions or thoughts.

Where is that turning point at which instead of helping us, it's telling us to do something? That's what I was thinking when I was talking about consent. Like I give you consent to read what I am thinking and let me control this but at what point does my consent end? I don't want you to also control things on my behalf. | Glasgow

Another element of control identified as an important criterion by many is the ability to turn a neural interface on and off (see section 3.3).

Personal choice was seen as an important condition for the acceptability of both medical and nonmedical NIs by the majority of research participants. In the words of participants in Glasgow,

Basically, people should have the right to choose what their body is, as it's their temple and they can choose whether they want to interact and use interfaces. | Glasgow

It was clear from the discussions that ultimately choosing for or against a neural interface is a matter of personal preference.

Each of us are individuals, we live different lives, we can make a better decision. You can't make an overall decision about how something can be tolerated. | London

In some groups the issue of choice was explored in relation to consent, particularly in relation to children who are too young to make decisions, or people who have difficulty communicating and/ or are mentally not able to make decisions. Participants felt more strongly about the need for consent in relation to internal NIs. They were deemed to be interventions that are less Then on the risk side of things there were concerns about permission from both people I spoke to. In the non-medical, both were worried about not being able to turn it off. There's a film, Minority Report, where you get arrested for thinking about doing something bad and she said, 'Oh my God, it's like that film.' London

reversible. There was a view that consent could be delegated to family and the medical profession, but autonomy and agency were seen as values that have to be adhered to first of all.

There should be a self-referral plan where you can alert people [to your consent to the use of NIs]. Or else the GP should be involved and the family, or the extended family. | London

For some participants, consent should take the form of proactively opting in or out of the use of specific NIs, much like people express their wishes in terms of organ donation or end of life treatment.

With consent, you know how people can have 'do not resuscitate', do you have something on your record that's like, 'I wouldn't ever want this,' or, 'I definitely would, give me everything.' | London

Across the research groups, participants spoke about the importance of transparency of information as a criterion for the acceptability of NIs. As a participant in London said,

Information and choice. First of all, knowing that's involved, what the technology does for you and if there are any side effects or downsides knowing what they are. Having been informed and given that information then having the choice as whether to use it. | London

Information and a collective consciousness of the nature of and relevance of NIs were seen as a prerequisite that enable people to have agency and make a balanced choice.

3.8 Ethical framework

Across research groups, people felt strongly that someone needs to oversee the ethical implications of NIs. They want someone to mitigate the risk that commercial parties might take the lead and drive developments beyond where society might want to go.

The overall thing is governance. There's got to be some body that oversees all this, otherwise it's commercially driven and if they can do it, they will. | Sheffield

They felt that clear governance of the technology would offer reassurance to both developers and people.

If we had a legislative framework then people wouldn't be as worried going forward with the production of NIs or coming up with innovative ideas. They would know there's something there to control it and it that would ease the public's worries. | Sheffield

This sentiment was reiterated at different stages in the research. Participants mentioned different governing frameworks, including a code of ethics for NIs, a regulatory body and legislation. Some recognised that strict regulation can stifle technological developments and therefore felt that a code of ethics was more desirable initially. A group in Sheffield summarised this as follows,

After developing this code of ethics, it's something that can run in parallel with the government developing regulation because if you develop a regulation that is too stringent you will stifle the growth of neural interfaces. You want to have that sweet spot in-between something being too constricting and also allowing people's choices to be protected. | Sheffield

In Glasgow, a group discussed that the relevance of an ethical framework for NIs will have to be tested on an ongoing basis as the technology evolves.

These moral and ethical codes will shift and change as these developments take place. Each collaboration will bring up issues that will need to be regulated somehow. | Glasgow

From a view that putting in place a code of ethics is less complicated and quicker, than legislation for example, they said that this type of framework would therefore be more suitable to capture what will happen over time. Figure 10 shows a visual summary of their thinking and the vox pops box gives a reflection of the words used when describing their view on a desirable future for NIs.

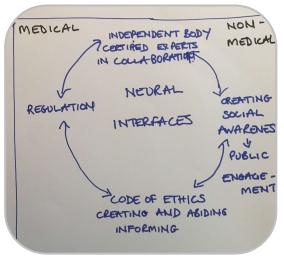


Figure 10: Summary vision | Glasgow

3.8.1 Elements of a desirable ethical framework

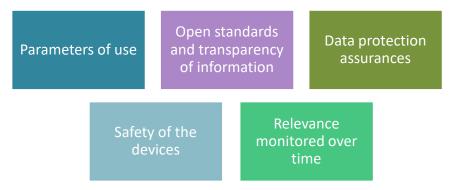


Figure 11: Elements of a code of ethics for neural interfaces

Throughout the discussions, ideas came to the fore on what would need to be regulated or captured in a code of ethics and who should be part of the decision-making.

Across the locations, participants said that it is important that restrictions of use are included in an ethical framework for NIs, indicating what purposes NIs can be developed for. This element should draw on the quality of life criteria identified by participants in this study and described in sections 3.4 and 3.5.

It has to be safeguarded. There's got to be some limitations to it. It's like the gun laws in America. The military can use whatever weapons they like, but civilians can't. In the medical world, hospitals and doctors can use opiates and we can't. There have to be limits. It has to be prescribed, or issued, or monitored, or timed. | Sheffield

To ensure equity of access to the research, one of the groups in Sheffield discussed that the publication of open standards, to enable equal access to information about technology applications, would need to be part of the code of ethics or a regulatory framework for NIs.

The concept of open standards, it means when you develop a technology you make it clear and open to the world, to everybody, what you have done and the steps to get there. It's shared and an Where stories, ideas and views matter [33] www.hopkinsvanmil.co.uk

open resource for everybody. These neural interfaces are so important that it should be a public benefit. | Sheffield

In their view this would enable the technology to deliver the equity of access criterion described in section 3.1. It will speed up the development in line with the way that medicine is only patented for a specific period of time.

It just guarantees more access to it. Could you imagine a world where aspirin was controlled by one company? You can go to the shop now and buy a pack of aspirin for 20p. At one point it was a patented medicine but it's now out of patent, so anybody is free to make aspirin if they have the technology. Maybe this technology, it's going to be like a drug, it could be used to modify the function of a human being and that should be regulated in the same way as medicine. Sheffield

In a similar vein, transparency of information was seen as an element that needs to be enshrined in a code of ethics for NIs.

They need to acknowledge all the positives but also the negatives so people can form their own opinions and not have a prejudice from certain agendas. | Sheffield

To avoid the misuse of data collected by NIs, participants said they expect to see data protection assurances being put in place as part of the governing framework for NIs.

If I agree to my data being used in a certain way having legislation reassures me that if the other party who signed the agreement misuses the data then I've got some kind of redress and it discourages them from doing that. | London

Others referred to the safety criteria discussed in section 3.6. A participant in London voiced the view of many saying that standards need to be set for publics to feel confident using NIs.

About the safety of materials used. They would have to have a kite mark, ethically and technically, yes. Standard, that's a high standard. | London

In all locations there was a view that an effective code of ethics for NIs should be developed with involvement from a broad spectrum of people, *dreamers and doers*. These would include representatives of the industry as a whole - medical and non-medical, scientists, ethicists, sector representatives from health, education, academia, transport, the military and members of the public with a level of understanding of the technologies. Ideally, participants said they would like to see an international body overseeing the work.

We had quite a lengthy discussion about the worldwide perspective of the focus being American, UK, EU, what about the rest of the world? China and poorer countries. Would there be any way that the whole world could come together and focus on a worldwide benefit versus, now having different countries following their own different rules. | London

In Sheffield, one group felt that it might be more practical to have separate working groups at a national level that meet to discuss different developments and feed back to the international body.

We thought it'd be really important to have as many nationalities represented as possible. [...] Probably taking the form of national focus groups. As and when things were being researched and developed, focus groups would meet and representatives would meet other groups. | Sheffield

Whether national or international, participants said that an effective organisation responsible for the implementation of a code of ethics has to be non-profit, independent from industry, and non-political and as such have no other benefit in mind than the public interest. In London one of the groups saw the Royal Society as a plausible candidate for this role.

It's having an independent body that gives the stamp of approval to both people practising in this industry and also companies doing research. We know that these companies have created social awareness and developed a code of ethics, similar to what's going on here. This code of ethics makes people more comfortable [...] with having either external or *invasive technology because* it's going to be reputable. Because not everything that's ethical is legal and not everything that is legal is ethical, regulation has to be developed in parallel as technology develops. If people were more aware, it would allow regulation to be created at a faster pace so that unwilling circumstances don't *befall people.* Glasgow

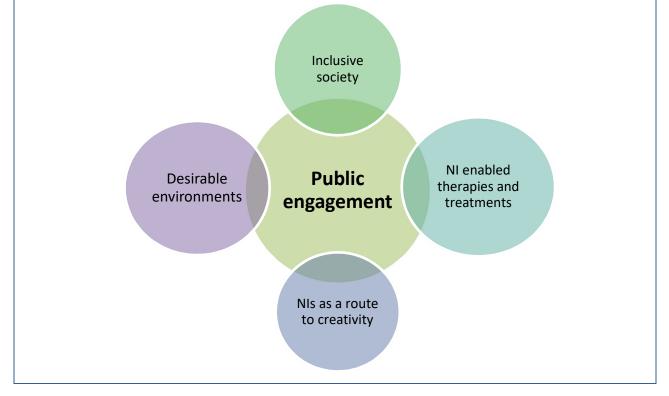
4. Desirable futures

Chapter 4 summary

In this chapter we reflect on the range of responses within the dialogue and special interest fieldwork which expressed optimism for desirable futures. This included the role NIs could potentially play in:

- Creating a more inclusive society where marginalisation is reduced or eradicated
- Developing therapies and treatments which are targeted, tailored and reduce costs to the NHS
- Developing our creativity both as a tool for artistic endeavour and as a way of opening up creativity to a wider section of society
- Creating desirable environments for a sustainable future.

But underlying these significant points is the clear statement from all those involved that public engagement, consultation and involvement should be central to the future developments in NIs.



Participants across public dialogue activities considered a future in which NIs are an integral part. This included deliberations on what aspects of NIs would be preferable so that they fulfil more of the criteria set out in Chapter 3 and summarised in figures 5-9.

4.1 To create a more inclusive society

When reflecting on desirable visions for the future, participants in all three locations frequently mentioned a wish to use NIs to eradicate marginalisation, particularly due to disability. A number of the vision statements created at the end of round 2 focused on this area. There was a sense that using NIs to link the brain and/ or peripheral nervous system to external devices which help people would be a path to a highly desirable future.

Examples of uses included:

- Helping people who are paralysed to walk or communicate; relieve depression
- Treating mental health conditions
- Improving cognitive abilities
- Alleviating hearing loss and the severe symptoms created by disorders of the nervous system
- Treating a vast number of chronic conditions.



Figure 12: Blue group 1 vision | Glasgow

A group in Glasgow said of their vision,

Your neutral interfaces essentially are taking away the disabilities. They're creating a more level playing field where everyone essentially becomes equal. When everyone's equal and you get rid of the marginalisation so that people aren't outsiders due to their disabilities, as perhaps they would have been otherwise. Glasgow



Figure 13: Green group 1 vision | Sheffield

In Sheffield one small group highlighted what was for them a potentially very positive outcome of NI technologies being employed to create what they described as a universally inclusive society.

Everybody will now be created equal. Underneath that, the big group of people, we've got a red cross, who are disabilities and things. There will be no disabilities anymore. Everybody will be included. Everybody who now currently can't speak, will be able to engage fully in a full, productive life. | Sheffield

In each location participants at some point expressed the view that inclusion also embraced enabling people to drive who hadn't done so before. They considered this in the context of health conditions and disability, so that someone who had been blind could use an NI to see, or someone who had been paralysed could regain their motor functions and therefore drive. They also saw driving as a route to a more inclusive society because the elderly could regain their independence by using NIs to improve their motor and cognitive abilities.

There might also be more people on the road because it helps older people drive for longer because they might not have trusted themselves to drive before. | London

An important aspect of an inclusive society and social cohesion for participants was improved communication. Participants referred to this in terms of making it possible for people who cannot speak due to damage to the brain and nervous system to communicate in non-verbal ways. This might include interpretation of brain signals to 'type' on a screen or keyboard-less typing. In all locations, improvements to communication were referenced as being a route to social cohesion. This was because they see communication as an essential part of understanding of difference, whether cultural or because of disabilities, and therefore part of a desirable future.

With the social cohesion we think that through [NIs] communication is enhanced a lot, you can communicate with people in so many different ways, unimaginable ways. | London

A group in Glasgow explored what they saw as an extreme, or moon-shot NI application, which would use an NI assisted external device to enable brain to brain communication without speech as part of what they saw as the 'ideal' element for their vision of the future. They discussed this as an instant form of communication which might break down social barriers.



'Telekinesis was the extreme ideal we mentioned. The sense of instancy, that exaggeration of a child-like mind of expectation. | Glasgow

Figure 14: Blue group 2 vision | Glasgow

Cochlear implant users were equally enthusiastic about advances in NIs which had supported them in their communication. They charted a progression from single-channel to multi-channel cochlear implants over the last twenty-five years and looked for a similar rate of advance in the short to medium term, not least because they saw their implants as a significant means of combatting isolation and helping them to feel more included in society (see section 3.4).

Others spoke of this in non-medical terms for example in overcoming language barriers so that an NI provides a form of simultaneous translation. In Sheffield they expressed this as desirable for society because it would create,

A deeper understanding of each other. Communication-wise, long-term, you'll be able to understand each other's languages, thinking as a result of that, it's a whole world concept, everybody's doing it. Sheffield

There was also a sense amongst dialogue participants that in a desirable future, when the technology has been miniaturised, if you are using an NI to combat hearing loss, the external device will be so small that any potential stigma attached to using cochlear implants will be reduced or eradicated.

If you've already got cochlear implants now, quite a lot of them won't be perceptible. You won't be able to tell a lot of the time. Most of the time, it will be hidden disabilities. If they had something big, you wouldn't be able to tell. You won't be able to see a cochlear implant; the thing will be a little dot in their hair. Glasgow

Participants in each of the locations and in the gaming community used the example of NI technologies for learning as part of creating a more inclusive society. They saw NIs in this context as providing opportunities for people with specific educational needs, but also more broadly in terms of widening access to learning opportunities. Gamers referenced this in terms of games which adapt

to the abilities and emotions of the gamer as well, enhancing their cognitive abilities so that they are in the optimal mental state when playing. One explained,

In the short term, designing technology that makes games more inclusive. I feel that NIs could create a whole new form of gaming, travelling, skill development and education and really is only limited by the creativity of the industry. | Pocket Gamer Connects

One group in Sheffield felt a desirable future for NIs would provide equal access to education by providing learning tailored to the needs of specific individuals, not just age groups or current attainment levels. They said,

With education we noted it could help someone with learning difficulties and that's part of a more bespoke learning personalisation, when it comes to education, which could lead to a movement away from the traditional forms of education. It offers new avenues in that sense. There's like an equality of opportunity. | Sheffield

4.2 Therapies and treatments

Participants reflected on a range of NI applications which might provide therapies and treatments for a wide range of mental and physical health conditions including depression, addiction, cancer, Alzheimer's disease and dementia. The view was widely expressed that this was one of the most highly desirable aspects for a future in which NIs are integral, in part because it was understood that NIs would have the potential to be very targeted in their delivery of treatment. People affected by Parkinson's disease stressed this element. They thought that treatments for mental health conditions such as depression sounded very promising as they believed current treatments had unacceptable side effects, which would be combatted by treatments which directly targeted specific parts of the brain, spinal cord or peripheral nervous system. Most were impressed and excited about the potential for NIs contributing positively to a desirable future. They said,

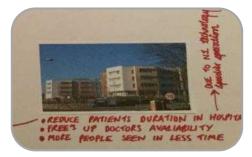
If the technology is there, let's use it. | Parkinson's UK group member

There was also a view that NIs being used to treat disease could help to reduce the time people need to spend in hospital, leading to a desirable future in which NHS treatment costs are reduced and funding for research is increased. They saw this as potentially being delivered by NIs:

- Monitoring health and therefore providing alerts to risks such as cancer where early diagnosis improves outcomes for patients
- Providing data to improve understanding of how disease can affect people in different ways and so providing more tailored treatments
- Providing targeted therapies to the brain for people at risk of or experiencing Alzheimer's disease.



A group in London set out this scenario in their desirable vision for the future,



We've got a central group of people representing a wide range of society and they can be from different cultures and religions, and also have different medical needs. We widely felt they would have some access to medical services, including NI, and they could be connected to devices that are monitoring them on an on-going basis, so we end up with faster treatments, less long stays in hospital and things like that. London

Figure 15: Red group 1 vision | London

People affected by Parkinson's disease predicted in their discussions that in 20 years' time any neurological and neuro degenerative conditions, such as multiple sclerosis, Parkinson's and Alzheimer's disease could be fully treated by NIs. Others in the dialogue workshops spoke of their optimism for a future where there is no need for mobility assistance devices because of advances in Mollii suits and equivalent therapeutic devices.

We believe that (by 2050) there will no longer be a use for wheelchairs or mobility assistance due to the suit being able to build muscle back into people's body and the spinal nerve connection. We could eradicate everyone's mobility issues in 30 years' time. | Glasgow

Participants expressed the view that NIs could, in the future, be relied on for providing a resource for people experiencing anxiety. A group in Sheffield thought through a scenario for someone who suffers from agoraphobia. They considered that NIs could be beneficial in providing a route for interaction that doesn't involve leaving the house. They predicted the person trapped in their own

I spoke to my sister Betty in a short telephone call. She was interested in the medical applications of NIs. Our family watched our mum deteriorate and die from Alzheimer's over several years. She was interested in NI technology and research in order to possibly reroute signals within the brain to slow down or prevent the disease and its ruthless effect, in the way that our dad had a pacemaker to help his heart. My sister would support development in this area. Glasgow

home being able to have meaningful interaction, on a deeper level than is available through for example social media and gaming, which could help to address the anxiety they are experiencing. They felt this was a very achievable near future goal and was part of a positive future. They said,

They can speak to people a lot easier, understand more what people are thinking. They will then be understood more, which would help treat the disease. They're communicating with other people, even though they're not leaving the house, instead of them being isolated, they are still communicating with people. They don't have that same anxiety as having to leave the house and be judged. | Sheffield

Gamers also discussed this potentially desirable aspect of future NI use. They felt that NI enabled games which recreated the world in a space where people felt safe could help in a number of ways. They suggested that these might include games which help people to engage positively with others, or react to and alter a user's negative mood as these two comments highlight,

Loads of games and applications can be used to treat mental health problems, as well as helping people overcome things and play with others in an avenue they did not have before. | Pocket Gamer Connects

I imagine games dynamically changing to suit the mood of the users. In the right hands we could use this technology to give users what they need to make them feel better. | Pocket Gamer Connects

Participants also reflected on the potential of therapeutic NIs for people who are addicted to certain behaviours or actions. They felt that using the NI could help re-wire the brain away from destructive behaviours. They suggested that the NIs could be used to:

Make it to where they don't enjoy that anymore. It's the same way to stop because people have found that there's a different rewiring of your brain when you have gambling addictions, too. That's why it goes across so many different socioeconomic backgrounds. It doesn't matter how educated you are. People get all of these endorphins from when they have that addiction. | Glasgow

4.3 A route to creativity

Enabling creativity was seen as an important aspect of a desirable future with integrated NIs for participants in Glasgow and London. Participants said that they expect NIs to make society more efficient and therefore people are likely to have the time, ability and inclination to express themselves creatively.

Once you've solved all the practical problems and disease and pain and inequality and disability then you have this world of people who can spend their time creating art and music and time for the creativity. | Glasgow

Small groups spoke of what they saw as an incredibly positive development in monitoring brain waves, in the short-term, and actual thoughts in the much longer-term. They saw in the future the ability to create physical entities from neurons firing, brain waves and thoughts. They saw this as having artistic value in, for example, filmmaking. Also, in game development, where you could imagine fantastic landscapes which would be created as part of a game scenario with greater power and impact than current virtual reality applications. They also felt that it would be potentially an important tool in making something currently transient and intangible, such as a thought, into a concrete object or 3D representation of that thought. This kind of discussion held in a variety of ways across the locations is expressed in the following interchange between a facilitator and a participant in Glasgow.

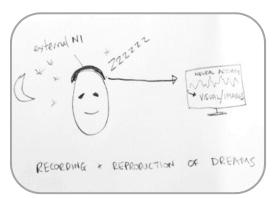
Participant: The art thing, it is that process of bringing something back as intact as possible. If you were able to get a direct line from the initial thought and create that in the physical world. You'd be able to conceive these things in quite a lot of extreme detail. A lot of science fiction artists and writers, what they're able to draw and write about is only a shadow of the thing that they want to tell people about.

 Facilitator: If your mind can see it, it can be put out there for others to see exactly as it was in your mind's eye?

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A participant in London developed this idea in their creation of a future NI application where an NI which could record dreams and create a visual representation of them on screen was imagined. Another London group also picked up on this idea describing a book they had read in which people's dreams are made into films and then the focus of people's lives become creating interesting dreams. For this participant this wasn't entirely desirable,



Their waking life and consciousness are targeted to create their dreams. It's kind of weird. How do you then progress your art? | London

For some the creative potential of future NIs was seen as really significant. One younger participant in the cochlear implant user group expressed her frustration in not being able to enjoy music as those with hearing can. She spoke powerfully of a revelatory experience one evening listening over and over again to a music track and finally, through that repetition being able to make out the melodic line. She felt that enhanced music processing would be enormously beneficial for the cochlear implant users of the future.

The pitch perception for music is difficult. I only pick up music if I listen to the same track repeatedly, then I start to pick up a melody, otherwise it's just a boom sound.' | Cochlear Implant User Group

For some, using NIs as an interface through which art is created is an enormous societal change. They reflected on the current artistic process, where someone's imagination and creativity produce something unique using specialised skills. They felt that in the future, human creativity could be fundamentally changed so that anybody using their brain waves could create art.

Any art that the human creates could be done in this particular way and I find that a huge thing. Could you imagine the effect that would have on the media industry? Everybody could publish their own art. You have a headset, you create a piece of art that you use the Internet to distribute, that's earth shattering. | London

The view was also expressed that using NIs could dramatically change the way we view various forms of artistic endeavour. One group explored this as part of a desirable future saying that there would be an enhancement of the immersive experience of art. By connecting to some sort of NI, you would not just see a painting or a sculpture, you could feel the sound and emotion expressed through it. They felt that you could also have the experience of live music at home.

You go to concerts for it live and blasting out at you but obviously you could do the same at home and go the same way of getting a multidimensional feel for it. | London

There was a sense that NIs could greatly enhance the value in experiencing art so that your empathy for the artist, the subject of a photograph, a character in an opera or play, or a film for example, is

increased through a direct link created by the technology as these two London statements, made by people in different groups explain.

If you go to a gallery at the moment you see lots of amazing pictures but (in the future) you'd be taken aback by but this is another level of emotiveness. There's this idea of no censorship. It's from the photographer or the artist straight to that person and no middlemen involved. | London

There was also a thing about being connected and excited to be part of the experience, such as being the actor in the film, beyond virtual reality sensors. Someone talked about being James Bond. | London



4.4 Desirable environments

Discussions on the environment came to the forefront when participants reflected on the potential environmental drivers of NI development. They saw NIs that enabled people to work flexibly, communicate more efficiently and connect remotely to machinery and robotics, so that there is no reason to go to a specific location to do your work. In their view this would be beneficial for reducing people's carbon footprint and help a future society to further reduce dependency on fossil fuels.

They also put NIs at the heart of understanding our environment. For example, using NI technologies to access environments which are not practical for human exposure for long periods or are completely inaccessible currently.

We talked about ocean and areas that are affected by radiation and pollution. Maybe we could use NI as a resource to locate it and help clear it out or improve it. Areas that are maybe too dangerous for humans to go to. Remote or dangerous places. Places like Chernobyl. | Glasgow

One Glasgow participant in a different sub-group developed a future NI application which would operate from your eye. He used a quotation from Buddhism as a starting point saying that we all contribute to co-creating our world and so all have a role in 'making the grass green.' He felt this NI would be used to understand our environment and through that understanding treat it with greater respect. The NI also had a secondary application which he thought could be used to help us feel better about our environment, or at least view it differently, perhaps even for fun. He said,

What I was getting at with this is we all are, we're all responsible. It's really our perceptions that make the world around us. I was linking it to the idea of what my friend was saying about mood disorders, being able to be treated by NIs. You could do it for fun as well, it could be a phone app just like Instagram filters. See the world as you choose. | Glasgow

4.5 Development underpinned by engagement

It was significant that participants in all locations and in the special interest fieldwork felt that it was an essential prerequisite for a desirable trajectory for the development of NIs, that user groups and the wider public are significantly engaged in the development process.



Figure 16: Frequently used words to describe the range of engagement activities required

4.5.1 Why and how engage?

The reasons for engaging in a variety of ways are summarised in figure 17 and described in the section that follows.



Figure 17: Reasons to engage the public on the development of NIs

It was striking how many participants put public engagement as the centrepiece of their visualisation of a desirable future. They said that the importance of the subject was so significant for the future of society (see chapters 5) and humanity (chapter 6) that a multi-way exchange on the subject was essential,

campaigns or social awareness, improving awareness on this I think is key, but the more people who knows about it, it's not so scary, it's not people making legislative decisions based on uninformed opinions. If you lack education on it and it's something that is unknown it's something that's more likely to be treated as scary and that would hinder it. So, having some social awareness campaign on what the possibilities are and what it actually means versus sci*fi.* It can be something that's just

positive. | Glasgow

I was going to say about having

I've got this sense that these issues are too important to just be left to any old scientists, governments, companies to think about. We do need this broader dialogue (with the public), and this should be the first step of a continuing process. | Sheffield



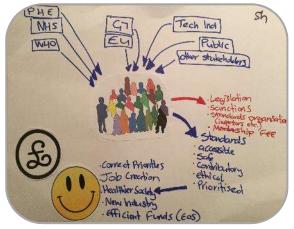


Figure 19: Red group vision | Sheffield

Figure 18: Green group vision | Sheffield

Vision statements from Sheffield (figures 18 and 19) demonstrate clearly the point that participants felt that diverse publics are as significant a stakeholder in the development of NIs as any other stakeholder from public sector bodies, decision making bodies or commercial enterprises.

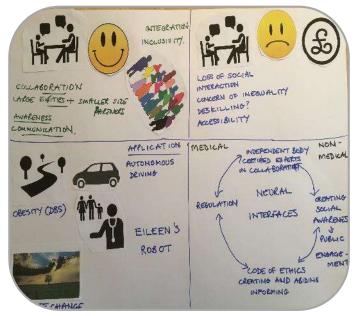


Figure 20: Red group vision | Glasgow

Groups in Glasgow also felt this. As we've seen in section 3.8 and figure 10, they spoke about public awareness raising and consultation in terms of ethics, but they also considered it more broadly. They discussed the issue in terms of ensuring that the decision-makers involved in deciding on the ethical, funding and governance structures that are required for the future development of NIs engage fully with a range of publics. They start with public awareness, feeling if that is set in motion then everything else will flow correctly to create a desirable future.

Many participants agreed with the logic presented in this vision statement (figure 20), that if NI development is to continue on this fast-paced trajectory to a desirable future, then public awareness is an essential first step. It was felt in a number of groups that if people can begin to use NIs for medical and non-medical purposes they are likely to become the greatest ambassador for what they can achieve.

For some groups this meant engaging people who are teenagers now who will be the substantial users in the future. They felt if awareness was raised in this group it would create benefits for all of us in setting the development of NIs on a positive trajectory. They felt that running a very public competition or high-profile campaign targeted at young people would be beneficial in raising the profile of NIs.

The way to do it would be to create some kind of a conversation or competition and bring them through that way. | Glasgow

Some participants felt that awareness should be raised so that in this dynamic changing field the people who will use NIs in the future will have the opportunity to stay abreast of developments, make personal choices about the adoption of NIs in their lives. They felt that a number of measures, including research, should be taken to ensure that buy-in is possible.

We'd also like to see somewhere that we're all reading from the same page. We'd like to see public surveys and a bit of engagement, so we know what we're getting. We know what's being unleashed on us before it does. Sheffield

If you were to increase public awareness and acceptance, it would push demand on worldwide key decision-makers such as the military, government, big businesses, corporations, and medical and STEM interests to make key decisions that would determine where the funding, research, and development. The money that goes to research and development will give experts the facts and figures to make their opinions for best practice ethics, control, and make a route for progress. Once everyone has (an NI) in their home and they love it, the optimism of the success leads back to public acceptance and it leads progress so you can *implement other things.* | Glasgow

There was a strong sense across the locations that in order to

make positive progress, and counter-act the perceived fears that people who are really unaware of NIs, but who suddenly are made aware of them might feel. One participant pointed out,

If you lack education on it and it's something that is unknown it's something that's more likely to be treated as scary and that would hinder it. So, having some social awareness campaign on what the possibilities are and what it actually means versus sci-fi. It can be something that's just positive. Glasgow

For cochlear implant users, consultation with them on how they would like the technologies to develop was seen as absolutely essential in order to get the developments right and understand the needs of this user group. They felt that it is essential for users of NIs generally and cochlear implants specifically to be involved in this dialogue between those who are creating the NIs and those who will use them. They stressed that it is only users who can report specifically on the challenges of using cochlear implants so that improvements can be made. They also wanted to encourage those that are developing the technologies to speak to each other, for example people spoke of the frustration they feel when their iPhone won't connect to their device which adds to feelings of isolation.

People also felt people needed to understand all perspectives on NIs, on potential opportunities and risks so that they could understand the extent to which, in these early days of widespread integration into society, they wished to allow NI-enabled applications into their lives. We touched upon gaming and more immersive experience, but we tempered that with a need for early, transparent public engagement to understand the positives and negatives, so they can formulate their own opinions rather than having an agenda forced upon them. | Sheffield

People drew parallels with climate change. They felt that if society as a whole had been more aware of the potential harms of plastics, for example, they would have been more vocal earlier on how much society began to rely on the material. The following participant's statement echoes the views of many on drawing this analogy,

Also, more information would help to drive this forward. The greater information the public have the more likely this thing is going to go forward. I draw a parallel with climate change, we have agreements on that, we should on this as well, and that's moving back into the political sphere. | Glasgow

4.4.2 Interaction between NI developers and the medical profession

In the specific instance of medical NI applications whether implanted or an external device there was a view expressed that the medical profession needs to be much better informed. Cochlear implant users raised this point frequently in the special interest group discussions. Cochlear implant users had direct experience of the lack of awareness of GPs of the daily challenges for users, for example that it is hard for some implant users to book an appointment over the phone, and that GPs frequently don't seem to know anything about cochlear implants.

For some in the discussions this pointed to an opportunity as raising awareness in society generally about CIs and in fact all NIs. One user spoke of a time before she knew about cochlear implants. She said,

I really knew nothing about cochlear implants, I thought I might get another ear or something. Everyone should now about these technologies and how they can help people.

Members of Parkinson's UK also felt that GPs should know more about the options for using deep brain stimulation to control the tremor they experience. Groups discussed the sense that GPs knowledge of the disease tended to be general. For some people affected by Parkinson's there is a significant role in ensuring that the medical profession know more about the NI trials available. They suggested that to make this work in practice might require an intermediary body, a broker between those developing and Everybody in this room probably has 101 different symptoms and none of them are the same. It strikes me that maybe the Royal Society, part of their role in doing this, is educating people in the (medical) profession, telling them what's available so they can try and match having a little bit of knowledge about something. You can say, 'Maybe that might work with you.' The trials for drugs are so expensive and so difficult to do, and the suits or whatever, may be quite good in a hospital if they had two or three that they could give to people, see if it works. Not maybe go and spend £4,500 buying one, but maybe trialling it for a week or two. It's for the medical profession to have the knowledge this stuff is available, and all these alternatives available, so they have a much broader brush of people's very *broad symptoms.* | Parkinson's UK member

testing NIs and those who might be advising people affected by Parkinson's of appropriate medical routes to take to alleviate their symptoms.

4.4.3 Engagement leading to social inclusion

Social inclusion is referred to extensively in this report (see section 4.1), but it is important to mention it in the context of engagement. Participants were clear that there are communities across society with specific interests in NI, for example the special interest communities that were involved in this research. The stressed that having an inclusive continuous conversation with these groups, as well as wider society was essential,

You get your communities and we have to make sure that it is an optimistic future. It requires a lot of participation; it needs to create a conversation and through doing that hopefully social cohesion. | London

This is to counter-act the 'haves' and 'have not' situation where only certain people can be

supported through NI enabled technologies because they either have the knowledge of them and/ or the money to finance it. They suggested that without wide-spread sharing of information on NIs people will become excluded from the development of NIs and their wide-spread use in certain sections of society is common, but selective. Participants made it clear that if NIs are to successfully benefit the widest sections of society in a desirable future then engagement needs to be central to their development,

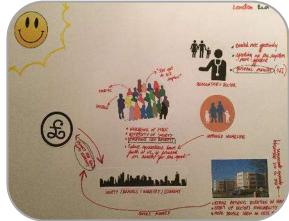


Figure 21: Green group vision | London

We're saying it's an optimistic future, that would mean there are big conversations about the technologies, so social cohesion of society as a whole. | London

4.5 The issue of trust

Previous public dialogues commissioned by the Royal Society have tested the issue of who is trusted to work on emerging technologies and their applications⁴. The findings for this public dialogue clearly marry with what was discovered for these technologies and as such are not repeated at length here. For the participants in this study researchers working on NIs in university academic settings are highly trusted,

So, for the ideal side we wanted more university researchers being on the forefront investigating and researching neural interfaces versus pharmaceutical companies, which seems the realistic thing in our minds. | Glasgow

Later in this report (see section 5.6 and figure 26), the cross-fertilisation between research being done in private companies and private sector investment informing and to some extent driving new developments in public sector, health and social applications is seen as positive. A desirable future

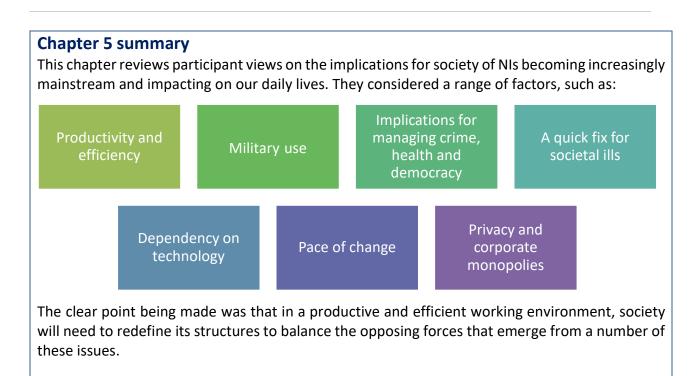
⁴ HVM: Public Dialogue on Genetic Technologies, 2018 Where stories, ideas and views matter www.hopkinsvanmil.co.uk

therefore encourages this cross-fertilisation and ensures that university and academic research is given support and investment to ensure the criteria for acceptability set out in Chapter 3 are met.

A group in London in their final vision statement said they felt an impartial body to act as an intermediary for all the actors involved in the development of NIs would be their ideal position, both to regulate (see section 3.8) and to advocate, to ensure that there is joint up thinking across sectors and in policy making. They suggested the Royal Society might fulfil such a role, with their ideal being,

Something like The Royal Society. Something where no one person can completely benefit from this would be great. | London

5. Implications for society



5.1 Productivity and efficiency

Time was spent in all locations considering the implications of NIs in the context of improving efficiency in the workplace. Participants raised the potential for NIs to be used for enhancing cognitive abilities and enabling people in various ways to work harder and faster for longer. They perceived this to be a precarious balance between a series of opposing forces of benefits to the UK economy and the potentially negative implications for society.

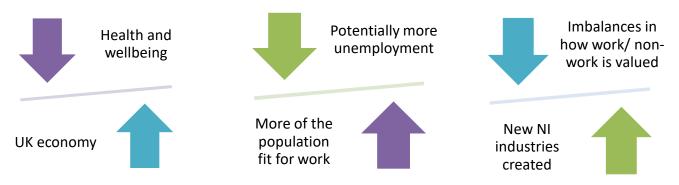


Figure 22: Opposing forces within productivity and efficiency

Participants felt that NIs are uniquely placed within the context of emerging technologies to impact on productivity and efficiency in the workplace. Discussions demonstrated that it was clearly understood that developments in artificial intelligence and machine learning could also have a significant impact in this area. But NIs, by potentially enhancing people's cognitive and motor functions, had a specific role which needed to be teased out. Taking the opposing forces summarised in figure 22 in turn demonstrates the range of implications raised by participants. Groups in each of the locations discussed the positive impact they felt NIs could have on the UK's Gross Domestic Product (GDP) and the national and global economy. For example, some participants spoke of the economic benefits of,

Making people harder workers, more efficient workers so you can build buildings more quickly, you can create more crops and harvest them more efficiently. | Glasgow

This was seen as positive. However, there was concern that the opposing force (health and wellbeing) would mean that people were forced into the position of having to work harder, faster and longer and there was a clear warning that this should be guarded against. In discussions, this concern was raised by some who foresaw using NIs to enable people to work faster or for longer by controlling workers' muscles. They felt this was fine if the person had agreed to this enhancement but worrying if not.

If the technology is used to exploit and oppress in the public space, for instance in the workplace NIs could be used maliciously to control employees and squeeze even more efficiency out of them. Pocket Gamer Connects

A significant point raised by groups in all locations was the idea that as NIs become increasingly used to treat paralysis and disease more and more people will become fit for work. This was seen as positive for many reasons, both for the individuals themselves who feel well and able to contribute more fully within society, and also for society as less money would be needed for disability benefits, and the NHS.

However, this could also be seen as problematic in terms of the number of jobs available, which could become a shrinking pool as efficiency increases, and the increasing number of people available for work. One person in Glasgow summarised the views of many in saying,

If (people whose disabilities are cured) no longer require that support you then have this massive pool of people who essentially maybe have not worked before, or if they did it was in niche areas, all of a sudden being able to do pretty much what everyone else can. It might have the effect of raising the overall standard of people available to work, but at the same time there will be a lot of them. There's an employment factor there. There are benefits and cons as well. | Glasgow

The third set of forces shown in figure 22 highlights the challenge of balancing the wide number of new industries and roles that might be created. These are jobs that we haven't as yet thought of, which will be required for all the NI applications that are yet to be imagined. They spoke of, for example, industries creating miniaturised micro-chips, biometric scanners, injectable chips, electroceuticals⁵ and gaming platforms and applications.

⁵ Small-scale devices that treat ailments with electrical impulses Where stories, ideas and views matter www.hopkinsvanmil.co.uk

For jobs, it was just obviously there are going to be less jobs, but there will be different types of jobs as well, new industries will be created. There will be the industry of people who are making the neural interfaces. | Glasgow

But this is set against a concern that this new society will have to think seriously about what it means to work, how work is remunerated and how we value or recognise non-work activities in this hyperproductive and efficient society where people will have more time for leisure pursuits. A London participant summarised the issues in this way,

This is going to create a societal problem in the sense of the way wages are traditionally structured. Are they going to pay us less because we're only spending half as much time at work? How are we going to pay those people who are not working at all? Are we going to completely reassess the relationship between productivity and pay? | London

For groups in both London and Glasgow, this led to reflections on Universal Basic Income, where everyone, whether in employment or not is paid a wage. Other solutions discussed across the locations, but particularly in Glasgow, related to incentivising industry to create the new jobs required, for people with NIs who are now well enough to work and for the people who could lose their jobs to more efficient working practices.

I think what we discussed is good in regard to grants and incentives. Create an industry for manufacturing NIs, it would create so many jobs and a totally new industry. Like having a new workforce, people that are going to be previously unable to work, it would go hand-in-hand with that as well. | London

The clear point being made was that in a productive and efficient working environment, societal restructuring will be required to balance these opposing forces.

5.2 Implications for managing crime, health and democracy

Participants also explored the societal implications of NIs on structures for managing crime, health and democracy.

5.2.1 Crime

The implications of NIs for crime prevention were often discussed across the dialogue. They included the key points made in figure 23, many of which participants saw as far future considerations, but nonetheless as points which should be reviewed at an early stage in NI development.

Definitions of criminal intent were considered by groups in each location. They reflected on the potential for NI technologies to be developed over the next 50 to 100 years which could mean that a thought we have becomes a criminal offence. As one participant in Sheffield put it,

Would I be able to tell a robot to kill my husband, or the woman he's having an affair with? Would it stand up in court when no one can prove that I thought anything, or would they be able to prove it? | Sheffield



Figure 23: Points for consideration in relation to crime in an NI enabled society

This consideration led to discussions about what a 'criminal intention' would be defined as in the future. Would a thought constitute a crime? Would the police be able to trace that thought back to the person who had thought it and prosecute? A participant in Glasgow reflected on what she would say to the police in such a situation,

I just thought it. I didn't mean to do it. It was just a random thought. | Glasgow

In some groups this led to discussions on to criminals being able to hack other people's brains and nervous systems and take over their bodies to make them commit crimes on their behalf.

If you can control all your limbs, broken down into simple electrical impulses, somebody could control my arm and make me stab somebody. | Sheffield

Others wondered how the police could or would investigate such a crime, where someone has controlled someone else. They found it difficult to construct a system which would enable the police to track this type of NI enabled crime. One reflection was that if NIs were in widespread use, then the police could use the same technologies to read minds and track criminal activity. The question then became whether the evidence gathered through NIs would be admissible in court. Participants wondered if NI data gathered to inform the police investigation would be used in the future in the same way that mobile phone data is used now.

Could you tell if somebody was temporarily insane as they were bludgeoning the wife to death? Could you fit a device onto somebody to try to understand what their state of mind was at the time of committing a crime? | Sheffield

Surveillance was also discussed as a result of the conversations around crime. One group in Sheffield talked about a 'brain ID'. This would be an implanted NI device which would provide a full picture of your thoughts over a period of time and act as a passport and identity card. They saw that,

There are civil liberties as a ramification of that. | Sheffield

However, the group in Sheffield felt that the need for surveillance in an NI enabled society, with the enhanced potential for undetectable criminal activity, was more acute and therefore necessary although, possibly not welcomed.

Surveillance, monitoring who you are, where you are, what you're doing and just being more aware of this person's activities, that this person is going there and buying guns. | Sheffield There was a sense that crime prevention, for example, without being carefully managed could step over a line and become dystopian. As this exchange in Glasgow demonstrates,

Participant 1: It could be a form of punishment to prevent repeat offenders, for example. If you're convicted of a murder, rape, or theft, then your punishment is that you get installed with this thing that prevents you from doing it in the future. Everyone.

Participant 2: Chemical castration.

Facilitator: Like an alternative to a life sentence?

Participant 1: It gets kind of horrific. | Glasgow

Exercising caution in this area and not overstepping a reasonable line which society has decided is ethical, and does not infringe human rights, was seen as essential and requiring careful management. Participants in each location saw that legal systems, criminal activity, policing methods and how we define crime would all need to be reviewed in a society in which NIs are an integrated part.

5.2.2 Health

Participants spoke about health implications for society across the dialogue, and these are referenced in other sections within this report. In terms of restructuring current systems to take into account fast-moving developments in NIs, participants felt that the future health system would have more resources. This is because they believe that with more people using NI technologies to move when they would otherwise be paralysed, to manage chronic health conditions and disease, to respond better to targeted treatments, including for mental health conditions to use NIs to see and hear and to manage obesity, there would be fewer demands on the NHS. The implication for society expressed by participants was that this would inevitably require a restructuring of our health and social care systems to focus on different priorities, such as summarised in figure 24.

Research into NI treatments Managing health into NI enabled increased old age Independent living for disabled people

Figure 24: Priorities for future health and social care systems

There was a concern that it would be important to manage this future structure so that the role of the NHS was not minimised. People were fearful that those with the money to pay for NIs privately would do so, meaning that the market would decide how our future healthcare would be managed, rather than government policy. As one group in Glasgow put it,

It'd likely be, if you can afford it, it's there, let the market decide. That would likely shape the future of it, especially with regards to the investment side, how much money is there to develop it. Glasgow

5.2.3 Politics and democracy

For some participants, NIs presented a risk to our democracy which they felt should be reflected on and properly managed. Participants in the first workshop in Sheffield considered news items over the last few years about social media platforms collecting data on their users. They extended this and thought that politicians would be able to collect data on voters, using NIs, and use it to persuade people to change their political allegiance. The fear around that for participants was loss of privacy, but also that,

Extreme views could push NI development, whoever's in charge, they could push their own agenda. | Sheffield

Another small group in Sheffield also discussed this, feeling this would have a profound and unwelcome implication for society.

I would be frightened of too much government intervention. If you can get information leaked directly into your brain, someone could leak some subversive information into your brain and affect the way you think, politically. | Sheffield

However, this was counteracted with the point that the public want to know that politicians are credible and telling the truth. The public could therefore require politicians to have an NI so that the public could tell directly from their brain wave patterns whether or not they plan to meet their manifesto commitments. They also considered,

In the long term, whether voting would still exist or whether technology makes the decision what's best for our country? That's quite controversial. I don't think people would want that, but it's an interesting thought. Is technology more intelligent, able to work out all these different factors, what would be best for a country, and make that decision. Sheffield

While most people were concerned by this idea one participant in the discussion saw a positive element.

If the thoughts are coming directly from people's minds, as opposed to the voting slips, people being influenced by other things and by political parties. You know what people genuinely want, as opposed to what they think they want, or be told that they want. | Sheffield

Participants in London also took up this theme. They could imagine a future where 100% of the population have an NI enabled device. They thought this could be used to continuously monitor people's views on the hot topics of the day. They said,

You could put the question to them and you can get, effectively, fairly continuous responses for all sorts of political questions. | London

A group in Sheffield also took this line of enquiry on the future of democracy. They could imagine all focus groups, elections and referenda working in very new, possibly incentivised ways. They explored all the population having an NI chip but described this as 'a bit sinister'. However, they did think that people could opt in to having such a chip implanted so that they could take part in nationally representative samples to test public opinion continuously, to test the mood of the nation and inform policy.

This feedback could be happening in real time and the government could develop policy from the data they receive from these people and in exchange of having this chip in them they could get money off their tax bills. | Sheffield

Participants felt these new democratic systems should be developed using open standards,

So, this knowledge, that is important and powerful, this knowledge has to be shared and so not in the control of one company or a few people that have developed it. | Sheffield

In all of these discussions was an underlying thread of concern that there may come a time when our democratic society no longer exists, and we are governed by dictators. Participants saw a risk here if the NI technologies for democracy are in widespread use and we lose our democratic systems because,

If the state's controlling this and suddenly there's a dictator who doesn't like you as an individual or your thoughts, that's a huge concern in this area. We're a country with a democracy and all the rest of it, but you can't guarantee that's always going to be the case. | Glasgow

5.3 Military applications

Participants were shown an example of NIs being developed by the US Defence Advanced Research Projects Agency (DARPA) which is working on near future NI applications such as remote drones for military campaigns and cyber security technologies. Of all the near future applications discussed by participants in Round 2 of the dialogue, this was the least well received. Participants expressed a range of concerns about it such as those summarised in figure 25.



Figure 25: Concerns about military NI applications

The de-personalisation of war was an aspect of defence applications predominantly focused on by groups in Sheffield, although touched on elsewhere. The concern expressed was that using NI controlled drones, robotics and cyber security systems, operated remotely from a great distance from a war zone could lead to the de-personalisation of war, making it feel unreal and remote. This was perceived to be a certain consequence for populations of countries that might be at war with a country far away from their own, but potentially also for the military personnel involved. As one participant explained on behalf of their group,

We all hated this development. I'm not going to make out that wars have been conducted democratically down the years. This seemed to suggest a step back. It's a sub-department of a government saying, 'We can do this. So, we'll go ahead.' You may not even hear about a war unless the media latches onto it, because it seems to be like computer games.' Sheffield

They continued with the thought that using brain-controlled NIs could be a secretive form of warfare, conducted under the radar and out of the public gaze. They said,

This seems to be behind the scenes. Unless the media latched onto it, the public wouldn't have a clue it was going on. | Sheffield

Others in Sheffield thought through this in more detail, saying that it was a good thing that using NIs for controlling devices remotely could result in fewer military casualties, but they felt there was the potential for such technologies to contribute to more challenges, including injury and death, for the civilian population. Collectively they felt NIs used in this context was largely a negative development, where those managing the systems potentially,

Become dehumanised. Like, 'Press that button and a few thousand people will be destroyed but we don't care because our military is okay.' We thought it was such a negative development and it would be driven by governments. The government can see something in this for themselves. It's more attractive to them, rather than something which would be for the greater good.' | Sheffield

Groups in London agreed with this sentiment. They were also unclear how budgets for NI technology development for military use would be allocated.

Isn't it like a black budget where you can't see what they're putting their money into when it becomes military? When it comes to military you have absolutely no idea where that money goes to. London

A slightly different perspective on the transparency of the technologies was brought to bear in Glasgow where they felt that using NIs in warfare or for terrorism could have dramatic impacts on local populations. They described a dystopian future in which they could conceive of NIs working, via people's brain waves, to disrupt infrastructure, government and undermine how society works.

I can imagine the future of warfare will really be on a public level, where if someone was able to stop the supply of food into a city or mess with the internal workings of a government from the outside. I think it will go beyond physical warfare of people killing each other, which is already done with drone strikes. Rather than terrorism being physically harming as many people as possible, just completely messing with the way a first-world country functions would cause more damage. | Glasgow

Participants were not universally negative about these applications of NIs. Some felt that they, like nuclear defence technologies, would act as a deterrent and potentially prevent NI warfare or terrorism attacks being enacted. It was also felt that those developing these technologies for use in military campaigns should be fully informed about their intended use. Participants felt this might mitigate the more harmful aspects of the technologies. A participant in London said,

One way to mitigate that would be to give knowledge to the people developing it so they're aware of the risks to society and the potential negative connotations or outcomes of it so they can develop a safe system. | London

Participants in London and Sheffield also spoke of the benefits of developing NI technologies which could be operated remotely and protect a soldier from harm. They also expressed the view that funding for defence applications for NIs could lead to research into NIs which would be of benefit to the wider population, such as NI enabled prosthetic limbs. One participant in Sheffield described the small group discussions which led to this point,

The short-term was better prosthetics, which linked back into the military one. At the moment you have prosthetics for people, who are injured in combat or in accidents, back and functioning in their daily lives. But the next step is getting soldiers back into the battlefield again and carrying on being soldiers. Eventually that would lead onto better arms and legs than humans have. | Sheffield

For the majority of participants military applications were not seen to be a priority and, as described above, there was concern that such developments could lead to stealth military missions which had not been approved through a democratic process, harmed civilian populations and opened up technologies to misuse. However, the last word on this subject goes to a London participant who expressed a resignation that these developments would occur whatever their views on the subject are.

I'm a realist, I accept the military applications, some are for defence and my benefit, but I don't really like them or want them. | London

5.4 A quick fix for societal ills

A view was consistently expressed across each element of the research that society may come to rely on NIs as a quick fix for everything that society finds challenging, or costly to manage. A member of a Parkinson's UK group spoke of their concern that investment in finding new NIs to treat the symptoms of Parkinson's might divert attention away from finding the underlying cause of the disease.

As we all know, I don't think one of us has the same symptoms and all these things seem to be concentrating on making profitable machinery. They used to open people's brains hundreds of years ago. That's my concern, that if you don't know what causes it, how can you treat it? Parkinson's UK member

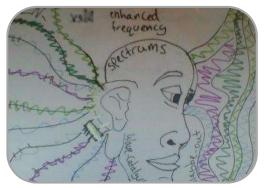
Another added,

We need to be looking for something that either cures us or gives us the illusion of being cured. So, we could live a life completely symptom-free, that's as good as being cured. | Parkinson's UK member

Others within the public dialogue agreed with this point, they also felt that the quick fix NI route may also drive business investment into their own NI developments and sway the trajectory of research. For example, participants in London spoke of the potential for researchers in tech companies deciding to work on mass market, highly profitable NIs, rather than others which might tackle a more challenging disease which effects fewer people statistically. They thought this might have a positive outcome, to get more effective technologies to market sooner, but they were not altogether sure that this was enough of a benefit and there was a fear that very serious diseases would not get the investment required. One reflected the views of many others in saying,

It's really about trying to drive the mass-market rather than the individual one. So, drive the sight issue rather than the Alzheimer's issue, because there's a huge number of people with sight issues, but a relatively small number with Alzheimer's. If you can do that you will reduce the size and cost of technology faster. | Glasgow

Participants considered the potential impact of using highly targeted electroceuticals to treat chronic disease. It was felt that this new form of pharmaceuticals may reduce people's personal responsibility for living well and taking their own disease prevention methods. For example, they saw a future where society would be using NIs in a consistently preventive manner so that people didn't have to get health treatment. They suggested that people would,



Carry on eating poorly, not exercising because heart disease will just be prevented and it wouldn't matter what you're doing because these neural interfaces would figure out what's going on, what's wrong and fix it before it even happens. That's in the science fiction end of it. | Sheffield

Participants in all locations thought about this in the context of mental health prevention. In Sheffield, participants talked about society becoming complacent about mental health conditions, treating it with available NIs (which participants imagined would be a medium-term and highly successful measure) without understanding why the number of people with mental health conditions is increasing.

The group continued to speak of NIs as quick fixes for people who are feeling a bit low and so wear their EEG headset for a while and feel better. A better solution, they felt, might be to interact with someone, go to the gym, or go for a walk or take personal responsibility for uncomfortable discussions you need to have with loved ones or colleagues. They felt that the quick fix approach to obesity and addiction might also be worse in the long-term for society. They thought it could change the nature of people and encourage them to seek short-term solutions rather than longer-term sustainable outcomes.

5.5 Technological dependency

Quick fixes lead effectively into another high priority implication for society: that people will become overly reliant on NI technology. There was a sense that this is not necessarily unique to NIs, as there is a tendency towards this currently, but this dependence would move across all forms of new technology, including NIs.



This was a view expressed equally by those who have already some dependence on NIs, such as cochlear implant users who said,

Participants testing a TENS machine, an NI on the market to alleviate pain | London

I am completely dependent for my life on the implant, but I still wonder if in due course this could affect our health, we could become more sluggish, children could become obese – they need more exercise, not more time spent with a device. | Cochlear Implant User Group member

Gamers also discussed this issue and saw the potential for a reliance on NI enabled immersive gaming as a route to addiction. There was also a concern that the more realistic a mirror of the real world an NI game became the greater the fear that,

People (will) lose their sense of reality. If everything is virtual this can increase the rates of mental illness. Clear boundaries need to be made in order for people to know when they are playing a game and not. | Pocket Gamer Connects

This was also seen as an issue for drivers, if an NI enabled car felt increasingly like a gaming experience what impact would that have on drivers? In Glasgow participants said,

I was particularly thinking of NI in cars, and having it controlled through your mind. It becomes like a game then, and it's not real, but there's a life in your hands there, when you're behind a wheel. It's not just a game, it's not a joke, it's serious, and if you put something between that you're becoming more desensitised and we shouldn't be becoming de-sensitised. London

The implications for society in this over-reliance on NIs was felt to be concerning when the technology fails. If society has been dependent on NIs, then life becomes very difficult if there are specific incidents of NI failure as described by one participant.

There is potential for it to become a crutch for a lot of things. If your pilot is flying over the Atlantic and using neural enhancement and halfway through, it fails, can they carry on? | Sheffield

However, there was also the sense that just like our dependence on the Internet, if there was a catastrophic global failure of NI technology, then that could lead to an equally catastrophic failure of society.

For some, the developments in NI technology were concerning because they feared that this might lead to humanity becoming complacent about their lifestyle choices as their *NI will fix it*. As a group in Sheffield said in their discussions on the use of NI for obesity,

Is it right to give yourself the means to not care? | Sheffield

In Glasgow this was discussed in the context of athletes not worrying about recurring injuries because they trust that through NIs they can get it fixed,

They're pushing their body to the limits because they know technology can fix it. | Glasgow

5.6 Pace of change

The implications for the pace of change were both positive and negative in the eyes of participants. In positive terms, there was a sense that high speed developments in commercial fields could provide funding for medical and less commercial social applications as summarised in figure 26. High speed developments in commercial applications

Figure 26: Cross-fertilisation between commercial and non-commercial NI applications

The two main concerns were that the pace of change will be too fast for the public to keep up with and/or that NIs will be used universally without an understanding of the implications. Participants felt that there is a risk that technology will move faster than public opinion or will suddenly be ubiquitous without society having taken the time to properly and effectively reflect on the frameworks through which decisions on future development should be made including ethical, legal and governance considerations. Two participants put it like this:

I think we're opening up a Pandora's box. Maybe some things are going to happen in the future that we can't even think about. We can't even imagine it, but in twenty years' time, we're going to look back and think, 'Oh dear. What did we do?' | Sheffield

I'm really excited where technology can go from gaming to human less typing, but yet I'm worried as it is going too far, and it just taking over completely. It's where your ethics step in as to what is too far. | Sheffield

One participant in Sheffield spoke of their concern that they personally may not be able to keep up with the pace of change. They spoke of their mother who is 63, but who is fearful of online banking and won't use it. The participant was concerned that their mother would lose the ability to bank soon if banking continues to be on a trajectory of online only.

They were fearful that they could be in the same situation in 30 years' time with their own children, left behind when society has embraced NIs but they can't get to grips with it. Others brought this fear to the discussions as expressed in the interviews conducted by participants with friends and family between rounds 1 and 2.

I interviewed a male engineer, my husband, and I was so shocked about the things he brought up. He was talking about downloading knowledge. If technology goes forward can you bring it back if it isn't doing what you want it to do? He was worried about all sorts of things like this, where the external device isn't ethical but dangerous. It shocked me. I told him, 'Bloody hell.' Sheffield

5.7 Corporate monopolies and data privacy

Some participants expressed concern about data privacy where people, through their NI, are under scrutiny by various sections of society including business and the state. For some this was extremely alarming,

I went straight to the dystopian view of having implants that track you wherever you go and listen to everything you say. | Sheffield

Others were less concerned, saying that they felt society would put the right measures in place to ensure that surveillance of populations was not used unethically. A more significant concern is that the data gathered as part of NI use would be used for commercial gain, to advertise products, to influence our behaviour and, given how marketing and advertising are already used in society, seen as inevitable.

We thought that an effort to move towards more commercial use would push it more in favour of advertisers because obviously, as more people use it, there would be more money to be made from people that use the neural interfaces. | Glasgow

There was recognition within the groups that this situation is not unique to NIs. People began to explore the ramifications of data gathered through NIs. They felt that, although NIs in the long-term had the potential to provide greater insight into your intentions - as they are linked directly into your brain and nervous system - it was agreed that this was already the case with, for example, advertising on social media.

Female 1: The more they know about your intentions, the easier it is to manipulate you into thinking this is something you want to do.
Female 2: Big Brother.
Female 1: It is.
Female 2: It's already like that. | Glasgow

Concern was expressed that large companies with money to invest would dominate the market for NIs.

Some companies have greater ability to financially buy those technologies and would then take over the industry and buy all the small companies, so there would be huge conglomerates. | Glasgow

One group in London used their vision statement to challenge this potential trajectory. They felt that if the government or nonprofit organisations could take early steps to dominate the market, they could avoid a corporate take-over, with the acquisition of patents and controlling shares in the technologies by a few major corporations.

However, they felt that a more realistic view was that, one person with personal wealth will dominate quickly in the market,



Figure 27: Blue group 1 vision | London

Inevitably, it's going to be a private person who makes it and owns it so there has to be regulation on patents and regulation to make sure that those people aren't completely self-seeking in what they create forever on and that everyone benefits from it. | London

6. What does it mean for humanity?

Chapter 6 summary

Participants felt that NIs are fundamentally different from other technologies, because working with the brain and nervous system touches on the core of what it means to be human. Discussions about a future with NIs therefore led to philosophical deliberations about the implications for humanity. In this chapter we describe participants' views on human transformation as a result of NIs under 5 headings:

Living in a without disability	 Will we attach a greater stigma to untreatable disabilities? Who decides which disabilities take priority in NI research and why?
Sense of self	 Do NIs lead to personality change? Augmented humans = humans shaped by learning and life experiences Loss of privacy, human autonomy and individual accountability
Disconnect from real world	 Addiction to enhanced reality NIs as a barrier between reality and accountability Diminishing social interaction and neglect of physical needs
Erosion of skills and human faculties	 Long-term physical and mental health impact Diminishing spiritual and creative qualities Unrealistic expectations? Difference between knowledge and intelligence
Power balance human and NI technology	 Relinquishing control, incl. over the ability to think critically and take moral decisions Loss of inspiration when human endeavour becomes eroded NIs as object of worship
Figure 28: Views on implications of NIs for humanity	

6.1 Living in a world without disability

Across the research groups, there was consensus that a widespread use of NIs is likely to cause a major shift in how humanity will view injury and disability. A participant in Sheffield said,

I think if it gets to the stage where something which is currently as severe as a spinal injury, which confines you to a wheelchair for the rest of your life, can just be cured 24 hours later give or take the bruising, that's a massive shift. | Sheffield

The more conditions and disabilities that are treatable, the fewer disabled people there will be. Although that will mean that fewer people will be defined by their disability, many participants felt strongly that this can lead to a society in which people become more intolerant and less appreciative of diversity. This was a seen as an undesirable future, as it may lead to a greater stigmatisation of those with untreatable disability or conditions. Participants said that this throws up ethical questions, e.g. who decides which disabilities will be prioritised for NI treatment and why.

Conversations with cochlear implant users showed that some had encountered resistance in the deaf community against their decision to accept a cochlear implant. They said that in the deaf community, identity is shaped by communicating in other ways than is the societal norm. In a similar vein, discussions about the use of EEG for education led to a view in the dialogue that this type of non-medical NI can potentially contribute to the creation of a subset of an ever more uniform society that is stigmatised and at risk of being bullied.

I met up with a friend who's a SEN [special educational needs] administrator. From her office, she sees the playground and there's one kid who everyone knows is really autistic and he gets bullied by everyone. Can you imagine that with a flashing light on your head? It can only get worse from there. | London

They concluded that the non-medical NI for education would need to be used either on everyone, or on no-one.

6.2 Sense of self

This ties in with what turned out to be a key question for many: how might NI technology affect our sense of self? In one way or another, participants across the research raised concerns about how a widespread use of neural interface technologies might lead to a loss of a sense of self. This is because NIs are seen as a technology that touches on what is most personal to human beings and what makes us different as individuals.

You could say everything's personal to you, your heart, everything else, but they're muscles generally. When it gets invasive, into the mind, the brain, that is different. That's where I get concerns, because it's how that could be misused potentially. | Sheffield

In some locations participants expressed concern about potential personality change as a result of using, for example DBS for mental health. They spoke about how adversity and dealing with mental health issues shapes our personality. The following discussion reflects this train of thought in relation to DBS for mental health.

Participant 1: I see it as negative. You become learn lazy, so instead of learning new and adaptive ways of being social, you're thinking, let me use this technology to even it out. It doesn't build character. When you're not dealing with your own internal strife, you may not learn these character traits that you can pick up, which is nice sometimes, to be funny or loud.

Participant 2: It leads to a stage we choose what personality we want to be. Implanted into us. | London

Others mentioned a fear of personality change, in the context of imposed behavioural control as mentioned in sections 3.7,

If someone's suffering from a psychological condition, how does it measure it and treat it without losing the person? Can that personality be altered by an outside influence, like a doctor, or the government? Am I still me? | Sheffield

For many a sense of self implies taking responsibility over one's actions. There was a view that allowing NI technology to impact on our behaviour reduces that element of what makes us human,

Yes, we can delegate responsibility for our own behaviour to technology. We could give up all personal responsibility. | Sheffield

Equally, another group pondered to what extent who we are is determined by learning and life experiences, and therefore, what the impact would be if NIs are used to enhance intelligence. Having watched the Economist video, which shows the potential use of brain computer interfaces to improve human intelligence by connecting the human to the internet, a group in London said,



I thought it was brilliant, in terms of the first video we saw. But how do we then define humanity if you download information into your brain? You don't have to learn anything; you don't have to have life experiences. You're just a cyborg, really. | London

Some expressed the hope that NIs will be developed in such a way that they will help people retain their sense of individuality in society,

Maybe neural interface can help with making us not all just a whole but allowing us some individuality within our own groups or families. | Sheffield

6.3 Disconnect from the real world

A major concern for many, including gamers, is a fear that some non-medical NIs will lead to disconnection from the real world. Because NIs can offer more immersive experiences in entertainment and leisure, including gaming, research participants saw a potential blurring of the boundaries between the real world and the world of NIs as a serious implication for humanity. Diminished social interaction with others was identified as a likely consequence.

How damaging could it be on society if it were something really immersive? People lose touch with normal human relationships. | Sheffield

Despite their overwhelming enthusiasm for NIs (see Chapter 2), many of the gamers in the study identified an increased addiction to the game and subsequent mental health issues as a risk of much more immersive gaming experiences. They touched on an addiction to the enhanced reality, which was discussed in the dialogue as well.

Mental health issues for users who get confused about what is reality. Addiction to gaming, we already have it, but the problem is that the immersive experience in gaming might be better for some than the hard reality of real life. Many of us are heading that way. | Pocket Gamer Connects

A group in Sheffield made the point that we use our body and environment to interact with the world. If that is no longer needed in a future where NIs are available for medical and non-medical purposes, the disconnection between real life and a reality created by NIs is inevitable.

Your body and your environment are what you use to interact with the world, but you don't need that if you've just got a brain in the jar. [...] That's the difference between NIs and other drugs. They [drugs] enable you to interact with the outside world. This [NIs] wouldn't, potentially. | Sheffield

Some saw the disconnection caused by NIs as a barrier between reality and accountability. Talking about their concerns that we potentially become more desensitised from the reality, a participant in one of the groups in Sheffield explained this thought in relation to driverless cars.

Behind the wheel, it already looks like you're detached from the outside because you've seen it through a window. You've got things in front of you but it's not like when you're walking and you can feel the wind in your face, there's a barrier there. Putting another barrier on top of that, being the technology, and doing it through your mind and sitting back, you don't feel accountable, like when you're holding the wheel and you've got the pedal beneath your feet you can feel that feedback. Sheffield

Whilst welcoming the fact that some NIs offer life changing opportunities to restore some patients' ability to communicate (see 3.4), dialogue participants as well as gamers talked about their worry that the risk of reduced social interaction and a separation from real life may have a negative impact of on mental health.

Gaming addiction is already something in society, but with games getting better, with all the new technology, it may increase people just being more recluse, gaming constantly, separating themselves from society. | Pocket Gamer Connects

For the medical side he was super impressed, but he thought the rest was just like VR gaming, he was like what's the point? He thought if the non-medical side becomes common and popular we're all just going to lose all our social skills and everyone's going to stay inside living in some weird fantasy world. London If you can communicate with people without having to go into public, or you can work from home, you'd never meet any new people. Perhaps some consequences beyond that, mental health, developing more extreme viewpoints perhaps. | London

The discussions about a potential disconnect from reality in a world where NIs become commonplace showed that for the vast majority of people humanity is defined by social interaction. This came to the fore as well in deliberations about the difference between virtual and authentic experiences, for example in travelling. They acknowledged that a world in which the experience played back on a neural interface has become indistinguishable from the real experience would be positive for

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our carbon footprint but saw increased social isolation as an important downside.

Not only will we cut ourselves off socially, but completely environmentally. We'll experience more but in a solitary way. | London

6.4 Erosion of skills and human faculties

A fundamental question for many was, *are we making ourselves redundant?* At various points in the discussions, participants raised concerns about the potential impact of NIs on people's physical and mental faculties. In addition to the fears of increased social isolation or *entombing ourselves* as discussed in 4.2, they talked about the implication for physical and mental health if NIs make lives so much easier that it leads to laziness and a more sedentary existence and a deterioration of our intellectual capacities. As participants in Glasgow and London said,

I thought aren't we taking so much away that we could be potentially dumbing ourselves down? I don't need to learn to drive properly because the car will do it for me. I don't need to turn on the TV because my thoughts will do it for me. | Glasgow

We've put no longer acting on instinct, becoming lazy, technology is guiding judgement. | London

Questions were raised about the potential loss of skills, including social, communication, muscular and motor skills. A participant in London expressed his concern about diminishing communication skills in the context of advances in technology as follows,

Can we just go back? This thing about change in us driven by technology. Very few of us can calculate now because we've had calculators for years. Very few of us can write anymore because we type everything. Recently we see the adoption of smart speech to control and ask and do things. If we then move to neural, as a way to control our environment, our tech, whatever, doesn't that just take away almost the final vestige of our communication skills? London

As such, the impact of NIs on communication and social skills was seen as an almost inevitable consequence of living in a digital society. The potential loss of muscular and motor skills, however, was felt to be unique to NIs. As a participant in London said,

What effect's it having on your muscular and motor skills, as well? If you're perfectly able bodied, this tech is training your brain to do what your hands can do. | London

It was felt this will profoundly affect what it means to be human. A participant in London compared text messaging to the keyboard-less typing NI and said,

I wrote notes on it earlier, humans are slow. It's taking out what a human is like, we're not perfect and don't need to be. If we're all perfect you're not being human. | London

6.5 Power balance between humans and NI technology

Deliberations on pushing the boundaries of what it means to be human showed that people are concerned about humanity being overruled by NI technologies. Of primary concern was the view that in a future in which NIs are widely used, humanity will to some extent be relinquishing control.

From a view that artificial intelligence can never fully replicate human behaviour, a group in Glasgow said,

Whichever way you look at this new technology, it's taking control away from a human to something else. Human instinct would be difficult to replicate. | Glasgow

They asked themselves how much faith we will put into NI technology.

Some software already predicts what you want to do, and sometimes it's not what you want to do. Are we going to have the same faith in what it thinks it [a neural interface] wants to do compared to what we want it to do? | Glasgow

This was something that was discussed across the locations with the majority of participants believing that programmed elements of neural interface technology should never be fully allowed to make moral choices. In a discussion about the use of NIs in driverless cars a participant in Sheffield raised this as an ethical question,

Where it [the NI] stops being a machine and almost becomes a person. [...] What does it use as its moral basis to decide? Do you tell the car, crash into a car with 4 people, rather than a coach with 60 people? Is that someone's bias fed into it or is it an independent decision? | Sheffield

There was a view that NI technologies put humanity at risk of relinquishing control over the core elements of what makes us human, including our ability to think independently and make our own decisions based on a set of moral values.

Some participants feared that NIs would deplete our admiration for people who have developed a skill through hard work and talent. Because such skills could be downloaded by anyone to our brains instantly, human endeavour would be eroded. Humanity might lose an important source of wonder and inspiration in the absence of human geniuses,

We have created people who we look to and respect for the special things they were able to do and if it becomes the norm to do things that surpass the things special creative people could once do then I just felt that was a little bit sad. | London

In Glasgow participants discussed how NIs might become a desirable fashion item, that everyone will aspire to have, *just to keep up with the Jones's*. They said that NI technology might take such a prominent position in society that it becomes an object of worship.

Similar to icons, you'll end up with technology which is the overarching God of society, where everyone wants to get to that technological peak. Perhaps many years in the future people begin to believe that technology itself is a God. | Glasgow

As explored in section 3.7, surrendering complete control to NIs was across the research groups seen as undesirable. In a desirable future for NIs, human beings need to have the final say. As a group in Glasgow said,

Whether it's desirable depends on whether humans have the final say. | Glasgow

For some this will create a more humane world. In the words of a participant in Sheffield,

If the routine stuff is being taken care off. You could go and read Shakespeare instead. The more automated things are, the more we can become people. | Sheffield

For others, as we've seen in section 4.3, the use of NIs to enhance convenience, for example through home automation, is dehumanising as they see it as a development that would erode human skills and faculties.





7. Conclusion and recommendations

Dialogue participants and the special interest groups consulted were all extremely interested in NIs. They developed clear views on the opportunities and risks for individuals and society in a future where the technology is widely used.

There was near universal approval, and strong admiration, for neural interface technology for medical purposes and though they tended to be received with greater caution, some applications of non-medical NIs were seen as a positive development for society as well. What was really surprising to most was the restorative nature of medical NIs and their ability to improve quality of life.

Some participants believed that NIs are an inevitable progression. They saw the developments in the internet, social media, artificial intelligence and neurological science as coming together and driving an unstoppable race to develop ourselves and society. What was identified as being distinctly different from other emerging technologies is the fact that neural interface devices link directly to the brain and peripheral nervous system, which most research participants perceived as a route to what it means to be human.

7.1 Questions to inform the debate about future uses of NIs

HVM concludes that there are four factors which will need to be taken forward into the debate around future uses of neural interface technology: no imposed behavioural manipulation; opting in – personal choice always; balancing innovation and public trust; and creating societal awareness. Further deliberation on these factors is necessary to reassure diverse publics that the technology is a valuable addition to their lives, rather than an undesirable intrusion.



Figure 29: Key factors to inform the neural interface technology debate

7.1.1 No imposed behavioural manipulation

The research has shown that the bottom line for the acceptability of NIs is the concept of our minds being protected from being manipulated by those who monitor and use data generated from NIs.

This response was present right from the beginning of the discussions through to reflections on desirable futures for NIs.

Research participants didn't object to medical closed-loop systems or responsive devices that help restore or protect physical or mental functions. They understood that these types of devices are essential for the neural interface to function. However, they did express concern about their minds being read or behaviour being controlled without prior consent. This was true for both medical and non-medical devices including EEG sets for gaming.

There was a view that the imposed feedback of data or commands to the NI as opposed to feedback of data/commands for which an individual has voluntarily signed up, for example to control obesity, changes the very essence of what makes us human, which was broadly seen as undesirable.

Can that personality be altered by an outside influence, like a doctor, or the government? Am I still me? | Sheffield

Although science is nowhere near being able to read someone's thoughts or command them to do something, this concern needs to be brought into ongoing discussions on the future of NIs.

7.1.2 Opting into the use of NIs: personal choice always

Although research participants found common ground around seven principles for acceptability of NIs (see Chapter 3), there was a strong sense that acceptability of both medical and non-medical NI applications is a matter of personal preference. It all depends on whether an individual sees their use as aiding their lives. The following interaction between the facilitator and two participants in Sheffield reflects this sentiment,

Facilitator: What would be too far?

Participant 1: It would vary from person to person. To me, being neurologically linked to another person, to know exactly how they feel every second of the day. To some people, being able to lay in bed and do everything you want from your bed would be too far.

Participant 2: It might not be in somebody else's eyes. They want that. It's the difference between you and I, between anybody, that has their own perception of what is too far. | Sheffield

As explored in section 3.7, surrendering complete control to NIs was, across the research groups, seen as undesirable. Participants told us that a future in which NIs are more widely used is only desirable if humans have the final say and pro-actively opt into their use.

7.1.3 Balancing innovation and public trust

The fact that the research showed that publics appreciate agency and human autonomy demonstrates a need for evidence-based, factual information. Participants acknowledged that society tends to be slow in adapting to some technological change. They said that at the moment

many people are unlikely to trust driverless car technology enough to put their lives in its hands, despite the evidence that shows that driverless cars are safer than conventional vehicles.

The technology's there and it exists, but the human race isn't ready to accept the fact that they can do this safely. We've got the mental block that says, 'I don't accept it. I want to override it.' I think that's part of the problem with driverless cars. We don't accept what the science is telling us. Sheffield

When digging deeper the study revealed that at the heart of this concern lies a belief that the decisions individuals make can't all be replicated by machines given that human decisions are based on a set of moral values formed by an individual's life experiences. At the same time, we learned that publics have high hopes for a future with NIs (see Chapter 4). These hopes focus on restoring quality of life – achieved with potentially fewer or no side effects when compared to current medical treatments; creativity; the environment; and the eradication of marginalisation. As the field develops and the use of NIs becomes more widespread in society the development of NIs will have to be carefully managed to avoid a genetically modified crop type scenario, where lack of public trust inhibited societal benefit.

To gain public trust and buy-in for NIs it will be vitally important to get the balance right between allowing innovation to flourish whilst ensuring research and development is robust and the implications for individuals and society are fully understood.

7.1.4 Creating societal awareness

The dialogue has demonstrated that a process providing accessible and robust scientific evidence, combined with creative tools to spark meaningful conversations, is an immensely powerful way to inspire participants' thinking. It enabled participants to develop a collective as well as an individual awareness of NIs and create new concepts for a future they had not considered before.

We have seen that a desirable future for NIs is one where the technology is integrated into our society and our individual lives with due care and consideration for ensuring they play a part in social inclusion, rather than social division. Equity of access to the technology was one of the key considerations in making decisions about the desirability of the technology, as were control, transparency and choice, and putting in place an ethical framework that is sufficiently robust but doesn't stifle innovation.

At the same time, it was felt important to use this opportunity to rethink the implications for how society manages work, crime prevention, health and social care and our democratic process. As the field develops and the use of NIs becomes more widespread these big questions, which at the moment seem philosophical and theoretical in relation to NIs, will come into practice. Participants therefore felt strongly that the development of NIs should be underpinned by ongoing public engagement. They stressed the importance of voices not only being heard in the current early stages of the debate, but as an ongoing process as the technologies continue to be developed.

7.2 HVM recommendations

To help inform the debate on the future of NIs HVM has developed recommendations on communication and language, ongoing public engagement and outstanding questions.

7.2.1 Communication and language

HVM has been impressed with the imagination and ability of the diverse group of publics involved in this research to reflect on a future with NIs. However, the study demonstrated that NIs as a term is not the most useful way to describe the technology. There was very low awareness of the technology amongst dialogue participants, patients and gamers and only a small number of participants had heard of NIs as a collective noun for these diverse technologies. Hardly anyone knew what the technology is without further explanation. As soon as a simplified description was used, e.g. 'a technology that links the brain to an external device' a lightbulb went on for most participants. Although the use of 'peripheral nervous system' is scientifically more accurate, the study showed that this isn't what elevates people's comprehension of the technology. Participants tended to talk about NIs as 'devices that link to the brain and the nervous system'.

7.2.2 Ongoing public engagement

Research participants were made aware of NIs as a group of technologies with medical and nonmedical applications. From the way discussions evolved it became clear that they didn't perceive all NIs to come from one group of technologies. They talked about medical and non-medical applications and emphasised that within those categories each application requires careful investigation and consideration. They expressed a desire for society to be involved in shaping the criteria for the acceptability of NIs for society on an ongoing basis as the technology evolves. HVM therefore recommends that key players in the funding of public engagement with emerging science are involved in finding ways to develop a comprehensive multi annual programme of ongoing public engagement to further elicit the views of UK publics on the outstanding questions identified in this study.

7.2.3 Outstanding questions

Our view on what needs to be explored further in ongoing public engagement activities is based on an analysis of the most frequently discussed themes in the study that will become increasingly relevant over the next few years.

- Equity of access: How does society create an environment in which the ultimate goal is that everyone who suffers from a debilitating medical condition or injury has access to NIs to restore or improve their quality of life?
- Control, transparency and choice: How can we make sure NIs develop in such a way that people have the opportunity to opt-in pro-actively to the use of the technology based on factual information about the pros and cons of applications and who has access to the data generated by their devices?
- Regulation: How do we arrive at a regulatory framework that is sufficiently flexible to enable science to progress whilst making sure it covers the elements participants in this study identified as essential: the publication of open standards, transparency of information, data protection assurances, safety of the devices and clarity about the purposes NIs can be developed for?

- Managing health in an NI enabled society: How is society going to redefine the current health and social care system to meet the needs of growing numbers of independent older people whilst ensuring equity of access to NI technology?
- Managing productivity and efficiency in an NI enabled society: What needs to be in place in a society that might have to balance a lower demand for labour due to automation and an increased efficiency of NI equipped workers with a growing workforce as a result of a more widespread use of medical NIs?

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