Neural Interface Technologies: Ethical and social dimensions

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Introduction

As well as the medical and technological possibilities they offer, Neural Interface Technologies (NITs) may entail a radical reconfiguration of existing categories, boundaries and ideas around health and bodies: not just between human and machine, but in how we understand ourselves as humans, what it means to be human and how we structure our lives and societies. This paper will explore some of the main axes along which these shifts are likely to occur, and the ethical and social dimensions of these transformations.

Body, mind and self

In the first place, the merging of human with machine that NITs offers has the potential to change how we understand our embodiment – as technologically augmented humans or as 'everyday cyborgs'¹. Granted, information and other technologies already do this to some extent: it is well known that use of tools changes our bodies as well as our brains. A contemporary illustration, for example, is the finding that smartphone use alters the way in which our brains process sensory signals from our thumbs². More generally, who we perceive ourselves to be, and what and how we think and do, are shaped by and incorporate the material and virtual worlds within which we are embedded. Various aspects of this interrelationship have been theorised as, among others, the concepts of 'extended self'³, 'extended mind'⁴ or 'extended cognition'⁵, each prompting us to reconsider where the boundaries of self, body and mind should be drawn. The advent of NITs thus involves not only a physical merging but also a conceptual disruption of boundaries, both of our physical bodies and our idea of our selves.

NITs that are internal rather than external go beyond these initial transformations in a number of ways. Firstly, breaching the physical boundaries of the body may entail a somewhat greater degree of risk. Side effects and safety are concerns with both internal and external NITs, but exposing the body to direct damage and chance of infection changes the risk profile in kind as well as degree. This in turn may affect our ethical assessment of these technologies in relation to different applications: what sorts of benefits are worth these risks? Second, depending on the context in which people are accessing NITs, they may require the assistance of health care professionals, possibly not only to implant but to remove the technologies if they so choose. This has the potential to change our relationships with our embodied selves, as the body becomes necessarily a locus of intervention by others. Further, the embeddedness of the machine component itself represents a shift in our relationship with

technologies, which are now "performing not only for us, but also on us and within us, chipping away at the inaccessibility of our internal bodies"⁶.

NITs also have the potential to change the ways in which we constitute ourselves with, via and through technology. For example, using NITs to record neural and brain activity creates the potential for a different, technology-mediated understanding of, and relationship to, human experience. Biofeedback, involving a combination of sensing, recording and modifying, goes a step further in allowing us to use machines to shape *how* and *who* we are in the world: the dynamic interaction between body, mind and technology forms a process of 'techno-self-constitution'. Beyond this, the possibility of using NITs to induce "new sensory modalities"⁷ promises to broaden the range of human experience itself and introduce novel ways of human functioning.

Using NITs to alter mood, behaviour or cognition, meanwhile, invokes fundamental neuroethical questions regarding identity, authenticity, freedom, autonomy and responsibility. If an NIT produces radical personality change, which persona represents the 'true self', and does this entail a change in identity? 'Who' makes the decisions when an NIT is being used to influence cognition, and who is responsible for these choices and their consequences? These questions have been extensively considered in the field of neuroethics, for example in relation to DBS and its effects on mood⁸.

Again, the deeper entanglement with 'selfhood' potentially associated with internal NITs may signal a greater challenge to the concept of autonomy with respect to these devices. If implantable 'smart' technologies are themselves making autonomous decisions within our bodies, how might this affect our conception of our own autonomy? NITs directed at behavioural change present further issues in that they can increase agency by enabling individuals to achieve the behaviours they want, but problematize the idea of the 'self' as autonomous decision-maker. Such philosophical challenges will begin to see practical exposition as these technologies come into more widespread use. We will also need to address legal implications with respect to allocating responsibility for decisions and actions. If a device function or malfunction affects a user's decision, leading to a negative outcome, does liability rest with the user, or with the device manufacturer? The issues here are likely to align conceptually with similar questions being raised in relation to artificial intelligence and responsibility for decision-making, especially, though not only⁹, in health¹⁰.

Health, disease, disability and enhancement

NITs also have the potential to redefine understanding of health and disease. Their introduction as health care interventions signals a possible change both to how we treat disease, and to what is seen as a disease. On the former, the timescale on and across which NITs can act differs from previously available treatments: biosensing implants can offer an instant response, providing a more rapid treatment intervention, while at the same time, implantable technologies may offer a longer-term overall approach to treatment. The possibility, meanwhile, that NITs might be used in the treatment of conditions such as addiction raises the issue of the medicalization of behaviour. What are the implications of characterising certain behavioural tendencies as pathological and in need of treatment? Further, if NITs can be used to influence behaviour, might and *should* they be used in wider contexts, not just health and medicine? For example, should NITs for behaviour modification be a sanction available to the criminal justice system? The potential for coercive use of NITs in such situations once again entails concern for freedom and autonomy, as well as the question of whether it is appropriate to use predominantly biomedical means as a 'treatment' for a complex social and behavioural problem.

Similar pressures may arise to use health-directed NITs, both from a public health perspective and for individuals through the normativity imposed by healthcare and medicine. Will patients really have a choice as to whether or not to use these technologies? Medicalizing human behaviour and the human condition in general opens up concerns over 'disease-mongering' (and the concomitant treatment-marketing it enables), as well as the threat to values that might be presented through perceiving the human condition as intrinsically pathological¹¹.

It might be the case, however, that NITs will in fact produce a more positive approach to diversity, through the various forms of embodied human functioning that they may enable. The use of NITs in assistive and adaptive technologies in particular opens up new and different possible ways of being in the world. A hi-tech wheelchair will not restore the 'normal' biological function of walking, but can enable mobility nonetheless. Prosthetics do not necessarily have to mimic the lost *biological* function for which they are intended to compensate, as long as they enable the desired *human* functioning in the context of the user's physical and social environment. NITs have the potential to contribute towards the ideal of seamless integration between users and devices, in these and in other areas.

The combination of NITs with assistive technologies may thus help to broaden our normative conception of 'therapies' beyond restoring 'normal' human biological function, to encompass the production of adapted, assisted or even enhanced modes of human biotechnological function. In so doing, it may reduce the stigma and negative value judgments often associated with differences that are typically characterised as 'disease' or 'impairment', and disrupt the assumption that 'therapies' *should* be used to 'fix' such conditions. Is it a moral necessity, for example, that a deaf child should be provided with a cochlear implant – and that they, or their parents, should accept it? Or are such choices value-neutral, examples of different ways-of-being, both of which can conduce to a flourishing life?

Rather than NITs being used primarily in pursuit of "enforcing normalcy"¹², then, we might come to see them as enabling human flourishing in a diverse range of forms and functions. While we might envision adaptive and assistive NITs

making us 'better than well', in their potential to create so many different ways of functioning, they may change our ideas about what 'wellness' itself looks like. The idea of human technological enhancement has sparked extensive ethical discussion¹³, and NITs offer considerable prospects in this regard for cognitive enhancement¹⁴ or 'cyber-enhancement'¹⁵. The possibility of altering and augmenting human functions and abilities via technology raises questions familiar in relation to human enhancement, such as about the value of human striving – what is the worth of achievement when we might think that "the machine did it"? The scope of applications and the scale on which these technologies might be applied will also require us to reconsider the criteria by which we define 'disability' and what we do (and should do) as a society in relation to this assessment. When biological dysfunction has been compensated by technological function, do we still class this as 'disability'? Such a question has not only philosophical but very mundane and practical ramifications: for example, how should eligibility for welfare benefits in relation to 'disability' be assessed? The potential of NITs to transform the very concepts of 'disability' and 'enhancement' themselves, as well as our attitudes towards treatment, should thus also be explored.

The datafied self

Another possibility that NITs present is the opportunity to harvest and use vast amounts of biodata, via the sensing and recording capabilities of the associated devices. This promises benefits to individuals in terms of monitoring their conditions and administering the optimum treatments, and also holds potential for valuable research. At the same time, however, it invokes concerns about privacy and how personal data might be used.

The use of health and personal data raises a number of significant ethical issues in itself¹⁶. NITs may further complicate these in terms of the types of data they are able to collect. Monitoring brain neural activity might be likened to a crude form of mind-reading¹⁷, with concomitant implications for privacy. The possibility, with longer-term uses, of constant monitoring and the implications of such surveillance, and, for internal NITs, the fact of being physically invasive and thus less under the subject's control, may also generate further concerns. Having access to this information about oneself may be seen as (and indeed may be) empowering: neurofeedback NITs, for example, can give users greater control over their state-of-body as well as mind. Questions arise, however, over who else might have or gain access to the data, and how it might be used. New kinds of vulnerability may be created, and new forms of risk emerge, in terms of the data that is created and collected.

Even when basic concerns over privacy and confidentiality and the harms that might result from data breaches are addressed, the 'datafication' of the self and society has broader social and ethical dimensions¹⁸. Using NITs and digital technology to record and to share data with others can enable novel modes of connectivity between individuals, leading to the formation of diverse digital communities and the emergence of new forms of collective human self-hood.

Scholars of digital health have tracked the rise of the 'quantified self'¹⁹ movement, but the full implications of these practices and the social, relational and conceptual shifts they may entail are yet to be fully understood. NITs, by adding another dimension to the data that may be collected, have the potential further to transform our individual and collective digital and quantified self-hoods.

Pathways to innovation

The ways in which NITs are likely to be developed and taken up imply a blurring between the domains of health and healthcare, and other spheres such as lifestyle and entertainment. Early forerunners of this trend can be seen in, for example, the rise of wearable health and fitness tracker technologies such as the Fitbit, and the use of augmented virtual reality in online gaming. In the future, NITs as wearables or implants might be used to monitor a much greater range of biological signals, while NIT to transmit sensory and motor stimuli promises to make virtual reality even more real. Whether the development of these technologies occurs first in the healthcare context and they are then repurposed for wider uses, or is driven first by lifestyle marketing, is likely to have consequences for the shaping of innovation in this area.

Another important nexus of transformation and boundary-blurring will be at the interface of research, medical care and health consumer technology. Will NITs, as 'liminal interventions' on their journey from the laboratory to the clinic or marketplace, be provided first to research participants in clinical trials, as experimental therapies to patients, or as products available for consumers to buy, whether on the legitimate, 'grey' or black market?

The distinction between research and medical treatment has never been entirely clear-cut, and attempts to delineate the two types of activities as separate for ethical purposes have always been somewhat artificial. A feature of the contemporary landscape of health innovation, however, propelled partly by digital technologies that enable the global connectedness of communities and the rapid communication of crowdsourced information²⁰, is the increasing prominence of a third context, that of health consumerism and the global market in health technologies, in mediating innovation²¹.

Again, these are not entirely distinct categories: in many countries, health care is already marketized at the individual level, while the rise of 'pay-to-participate' trials signals an increasing (and perhaps worrying) overlap between research participation and health consumerism²². What is clear, however, is that in thinking about the ethical dimensions of NIT innovation and how this might shape policy, we need to recognise the extent to which these domains overlap and interact. It is of limited use, for example, for research ethics committees to agonise over what level of risk it is acceptable to expose participants to, while simultaneously those potential participants may be accessing the same treatments via innovative medical care, or purchasing and using them as health consumers.

The question of via which domains NIT is accessed will have implications for regulation and governance: consumer products and medical devices, for example, are quite differently regulated, while research ethics committees have no say in what consumers can buy (or enterprising producers can sell) in person or online. These implications extend to the structuring of science, innovation and healthcare within society generally. The overlap of healthcare, research and the market, and concomitantly the roles of patients, research participants and consumers, is changing our ethical understanding of research participation, the science-society relationship and even what 'counts' as science.²³

For example, a prominent concern over alternative routes to accessing health technology is that insufficiently-tested innovations will become widely available without robust evidence of efficacy or, in some cases, safety. These alternative routes include exceptions created via health technology regulations, such as accelerated access or compassionate use provisions; loopholes in the international regulatory landscape, such as often occur in relation to medical tourism; or simply the global online marketplace. While one regulatory response might be to attempt to restrict alternative access and force all innovations to comply with the same pathway and standards of evidence, it is increasingly clear that this is not workable in all cases. For practical and ethical reasons, the 'gold standard' of randomised clinical trials cannot be applied to some treatments; meanwhile the pressure of patient demand for new therapies may defy regulators' attempts to control the diffusion of desired treatments²⁴. A pressing question, therefore, is: given that alternative access routes will increasingly be used in the dissemination of health innovations, can these also be used to generate scientifically valid real-world data to produce an evidence base to support (or not) their use, and how?

A source of particular concern is the trend towards the exercise of consumer power as an alternative to institutionalised routes for knowledge production and innovation that may be perceived as hegemonic and non-inclusive²⁵. The recent association of the DIY biohacking movement with the rhetoric of 'democratisation of science' is an illustration of this tendency. The worry, however, is that such practices are in reality more about commercialisation than democratisation, and that the power that citizens perceive themselves as 'taking back' in this way is simply being handed over to the free market.

Access for whom?

A final issue that must be considered in relation to NITs, as for any novel technology that may propel societal change, is that of justice. Who will have access to these technologies, and with what consequences for society? A common fear, particularly when innovations are seen as hi-tech and likely to be costly, is that they will be available only to those who can afford them. This creates a basic inequality with respect to accessing the technology itself; a further concern, though, is that having this access will enable the already well-off to gain additional advantage, thus widening inequities within society.

Are there reasons to be especially concerned about justice with respect to NITs, more than any novel technology? We are not preoccupied with ensuring equitable access to all forms of innovation: having the latest edition smartphone or this year's new model sports car seems a luxury, not a necessity or a right. NITs, however, precisely because they promise transformations in health and care that may be fundamental to people's capacities to exist as persons, to participate fully in society and pursue their own conception of the 'good life', are the sort of innovation regarding which we should be more concerned with ensuring equitable access.

Further, because some of the benefits NITs may produce are likely to have longer-term, even intergenerational consequences, we should also attend to the implications of access for the structuring of society. Consider for example the potential for assisted learning and cognitive enhancement: if effective, this is likely to confer a long-term advantage to users across their life course. If available more readily to those who can afford it, this increases inequity within generations, but also makes it more likely that those who are already advantaged and have benefited from the technology will be able to afford it for their children, multiplying disadvantage across generations. Although genetic enhancement has been held up as a particular problem for justice because of the heritable nature of the advantage²⁶, in fact many technologies (including NITs) will produce heritable advantages: not only might they result in epigenetic changes that can be passed on, but probably more importantly, the socio-economic advantages they confer are also inherited.

Concerns over justice are not, however, a reason to steer away from the development of NITs. There is much potential for these technologies to address individual and societal needs, and, depending on the manner of their development and diffusion, in fact to promote social justice. Careful attention to governance across all domains, with appropriate regard for the social and political dynamics that are driving the development of and the demand for NITs, will be crucial to ensure that NIT innovation emerges in optimum ways and delivers equitable societal benefit.

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