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Response to the Nuffield Council on Bioethics consultation on neurotechnology

Novel neurotechnologies: Intervening in the brain

from

Cesagen

(ESRC Centre for Economic and Social Aspects of Genomics)

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Cesagen response to Nuffield Council on Bioethics consultation on novel neurotechnologies: intervening in the brain

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Introduction

Cesagen is a multidisciplinary centre funded by the Economic and Social Research Council (ESRC) and is a collaboration between the Universities of Cardiff and Lancaster. Established in 2002, its remit is to examine the social, economic and ethical factors that shape science and technology. Our focus has been on genomics and genomics-related innovations, including ongoing work on stem cells and other developments in biotechnology. We have also been widening our remit to explore convergence with other emerging technologies such as robotics, informatics, and the mind-machine interface.

In what follows, we do not answer every question. We first proceed with our comments, referring to the numbered questions as appropriate. Thereafter, we provide examples from recent studies within Cesagen to illustrate more general insights for public policy. Excerpts from a case study (in appendix), illustrate some of the complications that arise in public consultation about human enhancement, in particular, with reference to idealistic perceptions which are strongly influenced by long-term popular imaginations about the future of humans and their societies.

As we said in a response to a previous consultation, our position is that attention needs to be paid to how the technologies and the associated issues are framed – ethically, politically, scientifically, and by whom. This includes how a given technology is itself described (typically well before it actually exists, if it comes to do so); the claims made for its purported benefits; how stakeholders are conceptualised; how social-cultural aspects will evolve. Such framing is not exclusively a scientific and technological matter but involves cultural and social imaginations as well as artistic ones. Framing ought to be a democratic societal and reflexive effort, involving collective public meanings, desires, needs and concerns.

General issues raised by novel neurotechnologies

The key points we foreground under each sub-heading in this section on general issues, are relevant to questions 4 and 5 by the council. They also address conceptual and philosophical questions, prior to questions of ethics or policy.

Convergence of mental, physical and virtual phenomena

Cesagen's research into BCIs and neurostimulation through work on the ICTethics and Technolife projects (FP7-funded), relies on similar definitions as the consultation document suggests, i.e., to distinguish between attempts to insert signals into the brain (here, neurostimulation) and extract signals from the brain (here, BCIs). However, we do not attempt to distinguish clearly between attempts to access the *brain*, and access the peripheral nervous system, other bodily functions or the body more generally. Many purposes for which research and experimentation proceeds, inserting and extracting signals, do not necessarily take into account these boundaries. Rather, ongoing experimentation and development of specific applications, raise expectations about convergence of physical, mental and virtual phenomena, with relevance for *medical applications*, *safety and security applications*, *reconnaissance and battle field applications*, and *enhancement options*. For example, we observe that Kevin Warwick's experiments in connecting computational functions to his own peripheral nervous system have implications for how we think of the role of the brain in facilitating a perception of the body (motor control and sensations), of the self and others (connecting with his wife's peripheral system). One can argue that his *brain* is indeed subject to an intervention. As he then argues himself, experiments with hybrid human-machine functions have implications for the future of security such as the potential ability to access places and objects from remote with one's 'mind'.[1] We also observe experimentation and developments that promise to deliver body implants with active biosensors, capable of collecting, processing and broadcasting data/information.[2] It is not far-fetched to envision applications that, for one or another purpose, read neuro-signals. If such implants find currency, whether that is for medical, non-medical, even recreational purposes, they will take bodies and minds *online* and thereby integrate them directly in what appears to be an indefinite expansion of cyberspace. We observe here a whole host of social-cultural, health, safety and security implications, blurring the boundaries between cyber- and biosecurity.

The convergence of nano, bio, info and cogno

We take the view that growing concerns about the development of novel neurotechnologies are intimately tied in with prevailing, diffuse but widespread, concerns about developments in the biotechnologies more generally, and potential convergence with other technologies. Government sponsored reports and policy briefs from the past decade contemplate and support (at least provisionally) future research and development of conjoined nano- bio- information and cognitive (NBIC) technologies. They engage a promise of improved social welfare and security, access to new opportunities, social inclusion and individual well-being.[3] They also speculate about improved physical and mental capabilities, modified and enhanced individuals and ever more military might, although, US-based views can be said to dominate

1 Warwick, K. 'Future issues with robots and cyborgs' *Studies in Ethics, Law and Technology* 4(3) (2010) . Available at: http://www.degruyter.com/view/j/selt.2011.4.3/issue-files/selt.2011.4.issue-3.xml .

2 The Braingate company in the US were the first to attempt the marketing of implants with biosensors for glucose monitoring.

3 See e.g., Bibel, W., Andler, D., da Costa, O., et al. (2004). *Converging Technologies and the Natural, Social and Cultural World*. Report EU Commission; Roco, M. C. and Bainbridge, W. S. (eds) (2002). *Converging Technologies for Improving Human Performance: Nanotechnology, Biotechnology, Information Technology and Cognitive Science*. National Science Foundation (NSF/DOC-sponsored report); Nordmann, A. (Rapporteur) (2004). *Converging Technologies – Shaping the Future of European Societies*. European Commission - HLEG Foresighting the New Technology Wave.

in that area.[4] It is therefore relevant to reflect on the conditions under which scientific-technological innovations arise.

Novel neurotechnologies in the context of contemporary innovation practices and innovation policy.

Growing concerns over neurotechnologies relate to speculative and future-oriented visions of these technologies, albeit with reference to success in assisting some patients with, e.g., Parkinson's Disease and severe motor or mental impairments. They are 'emerging'—more based in immature and provisional research-based scientific-technological knowledge, than matured and robust knowledge. They continue to be experimental while they are still passing into society where the learning and development needs to continue as part of the 'technology assessment' process. They are also more driven, shaped and promoted by a combination of funders, R&D practitioners, users, commercial beneficiaries and other stakeholders, than has previously been the case.

Key issues here relate to the *conditions of possibility*, cultivated in the shaping of strategic research agendas, policy frameworks, distribution of subsidy and the impression of an urge within the UK, Europe and US to be competitive at the cutting-edge of progress. We observe that the role of science and technology *in* society underpins (and is inseparable from) the widely accepted social value of depending on science and technology to solve societal and existential ills.[5]

Innovation practices in the area of neurotechnologies also raise questions about *conditions of accountability*, created in strategic planning and resource allocation *for the public good*. Governing bodies, technologists, industrialists, technology assessment expertise, legal, social and ethical expertise are all implicated in decision-making and policy development. But what are *accepted social values* is a moving target, negotiated and renegotiated, while uncertainties revolve around the culture of accountability in establishing political, social and ethical legitimacy of decisions on policy and regulation. We observe here two points that need further research, reflection and debate:

1. Disruptive innovation has taken on significant social value in its own right—to engineer developments with a view to improve individual and collective well-being, and the welfare of our societies more generally, through disruption. We ask if, prior to potentially disruptive interventions, visions of the future can be better democratised.

2. Hyperbolic expectations and promise are strongly indicative of how little is actually known about future benefits, risks and burden of the new innovations. In the case of neurotechnologies – also, info, cogno, bio and nano convergence – significant uncertainties surround the obscurity of what is *wishful enactment* and what is actually achievable.

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4 Khushf, G. (2007). The ethics of NBIC convergence. *Journal of Medicine and Philosophy* 32(3). pp. 185-96.

5 Von Schomberg, R. (2007). From *The Ethics of Technology towards an Ethics of Knowledge Policy* & *Knowledge Assessment*. European Commission Services; von Schomberg, R. (ed) (2011). *Towards Responsible Research and Innovation in the Information and Communication Technologies and Security Technologies Fields: A Report from the European Commission Services*. European Union (DG for Research and Innovation).

Case study excerpts (appendix) illustrate some of the confusions raised by common expectations of what novel modification and enhancement technologies can accomplish. The Technolife public forum on mind & body enhancement, analysed at Cesagen, shows clearly that techno-scientific realities, science fiction and techno-scientific utopias are not well distinguished in the public imagination. Moreover, on the basis of our organised meetings with experts as part of the ICTethics project, we argue that research communities (leaders and visionaries) tend to blur these boundaries as well, in the ways in which knowledge is articulated and represented, and the future depicted.

Philosophical questions engendered by the prospects of human enhancement

While we may have views about the principles that should be applied to human enhancement, there are also questions about what would count as an enhancement and the difference between the concepts of 'enhancement' and 'improvement'.

(The following are two extracts from Chadwick, 2010)

> Experiment 4[6] mentions a primitive form of telegraphic communication directly between the nervous systems of two humans. The author [Warwick] described normal human communication abilities, via language, as 'so poor as to be embarrassing, particularly in terms of speed, power and precision'. The successful result of an implantation would be a 'distinct advantage'.
>
> We have to ask ourselves if it is so obvious that this is the case. What might be the *advantages*, rather than drawbacks, of speech being slow and imprecise? This is a very complex question – there are issues about human relationships, of course, but also of culture.
>
> As regards human relationships, the first point is the implications for the possibility of keeping things private. Although the way we currently are has downsides, such as the possibility of intentional deception of each other, there are also upsides to the possibility of privacy of thought. The forming of relationships and the very possibility of deep relationships, presupposes that we are not completely open to everyone all the time. How would this thought transfer be controlled? At present, communication is a complex mixture of speech and body language, in the interpretation of which some may be more skilled than others. It takes time to get to know someone really well. Why should speed be an advantage *in general*, rather than in certain very specific sets of circumstances? The immediacy of comment facilitated by such developments as Twitter has not been universally advantageous to those who have chosen to reveal their thoughts.
>
> When we turn to culture, the phenomenon of human speech and language, and the multi-faceted possibilities of analysis of layers of meaning, have been at the heart of

6 This passage is taken from R. Chadwick's response to Warwick, 'New questions, or only old questions in a new guise?' *Studies in Ethics, Law and Technology* 4(3). Available at: http://www.degruyter.com/view/j/selt.2011.4.3/issue-files/selt.2011.4.issue-3.xml . Warwick's paper is published in the same issue: Warwick, K. (2010) 'Future issues with robots and cyborgs' ibid.

> human culture, tracing back to oral traditions, through the development of the written form, up to the IT era. The possibilities and difficulties of translation provide a focus of study themselves. Should we regard direct thought transfer as the inevitable next step? What might be lost?

In addition, in relation to any new development the question tends to be asked whether there are any new questions, or only old questions in a new guise. For example, Kevin Warwick[7] has written about an intelligent deep brain stimulator. Do such brain-machine interfaces really give rise to questions that have not been encountered elsewhere (even if they have not yet been adequately answered)? [8]

> We are familiar, after all, with the effects of mind-altering drugs. Experiments with transplantation of neural tissue, also, to treat Parkinson's disease, are ongoing. There are, of course, real risks here – the side effects of drugs, the possibility of transplanted tissue leading to a tumour or other pathogen-transfer, or to genetic change – but are the issues different in kind when we are dealing with brain-machine interfaces? The core of the issue here seems to be the description of the machine's job as to 'out-think the human brain'. Drugs and transplants do not do that because they are not 'intelligent', as the stimulator is described as being. Much depends then on the description and how it is and should be interpreted. The results of different kinds of intervention might be the same - or so similar that there may be little or no noticeable difference. If so then the question will be, in what ways, if any, does it matter that the result is achieved by this means?
>
> We go through life accepting, with more or less grace, that our bodies and psychological states will undergo enormous changes as we meet with situations and environments. Some of these will affect our freedom of action to greater and lesser degrees. The fact that an intelligent machine is preventing my brain from doing what it 'wants' to do is something I may accept because my natural brain is not doing what 'I' want it to do in any case – the functioning of the natural brain according to the description of this case is just as much a threat to the 'I' as is the intelligent machine. This way of looking at it does pose questions for how we are to understand the 'I' – but this is certainly not a new philosophical puzzle.

Modifications-as-experience: freedom of movement, morphology and choice (Questions 8, 9, 13, 14)

In the literature on novel neurotechnologies, we observe how concerns about human enhancement are almost exclusively cast in terms of improvement options that need to be addressed, debated and governed. This issue is particularly relevant to question 8 on expectations and concerns for BCIs, and question 13 about neurostimulation for non-medical purposes. What concerns us is the lack of engaging the notion of *modification*, rather than

7 Warwick, K. 'Future issues with robots and cyborgs' *Studies in Ethics, Law and Technology* 4(3) (2010) . Available at: http://www.degruyter.com/view/j/selt.2011.4.3/issue-files/selt.2011.4.issue-3.xml .

8 This passage is also taken from R. Chadwick's response to Warwick, 'New questions, or only old questions in a new guise?' ibid, footnote 7.

enhancement, and *modification-as-experience* rather than *improvement* options for strictly practical purposes. These distinctions were starkly foregrounded in a recent Master Class on implant technologies at the Wellcome Centre in London, organised by Cesagen on behalf of the ICTethics project.[9] What appears to happen here is the omission of artistic imaginations and social-cultural imaginations about future bodies and minds. Consequently, a range of reasons for why people consider or seek modifications, risk being omitted from the academic and policy discourse.

We observe a range of treatises on the treatment-enhancement continuum versus treatment-enhancement disruption. One example came up in the Technolife forum, to compare eye glasses with contact lenses, with laser corrective surgery, with a bionic eye. Can we say for sure that only the last on the list represents radical disruption, or perhaps the last two because they both involve irreversibility, thus a potential threat to the integrity of the person? While these are worthwhile considerations, it concerns us that there is a risk of omitting the continuum on which modifications (rather than treatment and enhancement) are more and more invasive. For example, they can shift from the piercing of genitals or the implantation of passive objects for modified sensations, to specialized materials (e.g. magnetic) to be activated for modified sensations and activities, to connect directly with the peripheral nervous system to control and connect with the environment in 'intimate' ways, to implantation into the brain to modify motor capabilities. It is important to note here that modifications, as they currently happen, are assisted not only by medical staff but in some cases by body modification artists where the boundary between medical and non-medical procedures risks blurring as well.

It is very clear to us that possibilities for both non-invasive and invasive BCIs to enhance performance in reconnaissance and battle field operations, draw attention to both physical risk factors associated with implantations as well as other risk factors associated with the increased intimacy of the human-device relationship. But while the military technologies include experimental development of applications for the purposes of: 1) positioning and tracking objects and bodies; 2) sensing and recording behavioural metrics (e.g., to decipher intentions); operating unmanned vehicles; 4) operating bomb sniffers and environmental sensors, the *key-enabling technologies* involved here are also developed in one or another form for civilian use. This is evident, for example, in cumbersome and often laboratory-bound work with disabled persons, using both non-invasive and invasive BCIs, as well as the latest gaming practices that use non-invasive BCIs.

We take the view here that an area of significant cultural currency and vogue is an *experience economy* whose role in shaping near-future and mid-term developments of body and mind modifications cannot be underestimated. *New experiences* are typically marketed through personalized services and products and counter-cultures come and go around particular fetishes. In this respect, it is a legitimate question to ask, to what extent body modification artists can take their craft, implanting 'smart' objects, how popular their services could become and what the implications of that might be. It is also relevant to ask what the relationship is between choices of modifying sensations and physical activities, and what we already know about the uses of fashionable drugs that are taken for mind- and experience-altering purposes.

9 http://neicts.lancs.ac.uk/masterclasses.htm#masterclass1 .

Freedom and choice

Choosing an intervening option to modify one's neurological functions, will have to take into account that in medical settings it may be difficult to assess how well informed someone's choice indeed is or in what sense people can be said to have a choice about decisions to intervene. Their choices are not likely to be made on the basis of information alone either, but under the influence of advice and encouragement to make a *good choice* in the situation on the whole. Nevertheless, the person is deemed responsible in the face of determining challenges such as developing Parkinson's Disease and severe motor or cognitive impairment, until otherwise diagnosed.

This example foregrounds how widespread assumptions about entrepreneurial selves and the framing of issues in terms of individual choice are challenged by different meanings of 'choice' and how these are mobilized for different purposes—here, the *good choice* in more or less *in-control* situations.

Research at Cesagen has addressed at length different meanings of 'choice' and how they feature in governance and regulation:

> One position, identifiable with a 'liberal' political philosophy, is that the job of government, in relation to food (analogous to its job in other areas) is to ensure that the food that consumers eat is safe – but beyond that it is up to the individual what he or she eats.[10]

Chadwick goes on here to compare various approaches to governance and regulation with respect to how autonomy and choice is conceived. The conception in the excerpt above, she calls "a 'thin' account of individual autonomy", where choice is confined to choosing for or against technological development or application on the basis of the information made available about it. This conception of choice takes for granted the empowerment of information and the technology itself, with ethical concerns centred mainly on accuracy, reliability and safety. We observe similarly that non-medical purposes for novel neurotechnologies are typically discussed with the presupposition of autonomy, that the agent's choice is primarily concerned with efficiency, productivity and competitiveness as integral to the preservation of optimal health and well-being. To presuppose that these concerns apply to most people is a mistake in our view, and when contemplating non-medical modification choices, it is not clear what is actually an improvement, in what sense there is enhancement, and so on. Giving advice and encouragement to make a *good choice* is particularly problematic when we are not clear on what is realistically possible. Non-medical purposes also involve social-cultural imaginations, artistic imaginations, peer group pressure and so on, and relate to lifestyle choices with significant implications for selfhood and identity. For example, our participants in the Technolife forum on body and mind enhancement debated the terms, 'freedom' and 'choice' in hinting at social pressures to conform to certain body and mind types, as opposed to the possibility that enhancement choices will bring about new and unexpected configurations of humans. Some also remarked that we might choose enhancements that cannot change our societies, only deepen already

10 From R.Chadwick, 'Nutrigenomics and statistical power: the ethics of genetically informed nutritional advice' *in* D. Bagchi et al., *Genomics, Proteomics and Metabolomics* (Wiley-Blackwell, 2010) pp. 23-33, which examines the different notions of choice at stake in relation to an emerging biotechnology.

entrenched societal and environmental problems, thus leave us with less rather than more choice. In that sense we make collectively informed choices with collective rather than individual consequences.

Bodies and minds online

We argue that it is essential to take into account that future developments of both BCIs and neurostimulation will involve data gathering from the body or the brain in one or another form, and computational functions that manage data and information. Our concerns in this respect have resonance in common problems associated with advanced sensory and data-management capabilities of information and communication technologies (ICTs).

ICT developments are notorious for challenging privacy and security. Identity-based data can be misused or incompletely processed and loss of privacy and equality is inevitable when citizens/consumers are subject to surveillance and sophisticated personal and activity profiling. Expansion of information services will also increase the risk of spamming, disclosure of private data and malicious attacks. 'Smart' applications can always go wrong or they do not function as expected. People are excluded from services due to lack of interoperability, inadequate profiling and data mismatches. Access to the technology is also persistently unequal. To summarize, the key ethical concerns centre on dignity, privacy and data protection in operating implants for health management purposes and on careful deliberation on the uses of implants in selected social groups, for security and for tracking. There are questions of access to advanced therapies; quality-of-life issues such as autonomy and independent living, risk management, safety and liability. As for both medical and non-medical applications, it remains to be clarified, however:

- Who is responsible, when implants fail to deliver the desired result or experience?
- Who owns data implanted in the body or collected from bodily/brain (neural) functions?
- Who accesses these data?
- Who is responsible when data propagate through constellations of services or get lost in data infrastructures?

Human-device intimacy

The more intimate the human-device relationships are, physically and emotionally, new issues of ethical relevance begin to take priority, including:

- Changing perceptions of body, self and/or identity
- New tracking, monitoring and adjustment capabilities of bodies, behaviour and state of being.
- New experiential opportunities (e.g. how far can body modification be taken ?)

- Dangers of unequal access and lack of both distributive and commutative justice (health-related applications)
- Changing perceptions of warfare, policing and related safety and security operations (e.g. including BCIs in remote operations), endangering further alienation and distrust between operators and their subjects.

To summarise, the most common issues we observe in our research, centre on the technicalisation of the body, human self-understanding, risk management, potential irreversibility, and an overarching question of the body as a resource, rather than sanctuary.

The respect for the dignity of the human is intimately tied in here with respect for self-determination. Therefore, particular complications arise in relation to the deployment of 'intimate' brain-computer interfaces and body-brain modification technologies more generally, in particular, when modifications are for military or other commission, command and control purposes –also, when operators, carers, relatives and anyone in a supervising role can configure devices and systems to intercept and interrupt the goings-on of other persons and, thereby, make decisions on their behalf which may leave them compromised in some way.

Commission, command and control purposes of modification and enhancement raise questions such as:

1. How decisions are made about commissioning someone to be modified for enhancement purposes?
2. Who 'owns' their capabilities and who is responsible for them?
3. How are decisions made about 'decommissioning' them when they are no longer in command and control?

BCIs for severe motor impairments also raise a range of problematic questions such as:

1. What are the risks of psychosocial affects relating to disappointment and frustration when a BCI fails to deliver in spite of extensive training, when devices and systems are withdrawn after a successful trial, and so on.
2. What are the hopes and the promises, and the extent to which quality of life can actually be improved with more independence, privacy and social participation.

Robust policy and decision-making criteria (Questions 10, 15)

Precaution

We take the view that looking at the potential issues here and anticipating future problems is integral to the reflexive practices of anticipating *futures to be avoided* and to exercise precaution.

Pragmatism and preparedness dictate that we embrace progress as long as it is a viable good, and that we critically evaluate what developments actually achieve for individuals and groups. A pragmatic stance can balance optimism and pessimism, hopes and fears, use and misuse. Preparedness and prudence also dictate that response to progress, in particular, the change engendered by new developments, occurs through the enactment of effective policy.

Questions and problems inherent to the development of BCIs, neurostimulation and neuro stem cell therapy include:

- Effects and side effects, runaway effects and other unintended consequences
- The validity of presumed social acceptance or individual consent, given that subjects include deeply vulnerable persons
- Are we prepared to contemplate how access to state-of-the-art technologies should be addressed, deliberated and articulated?
- How will legal claims be handled in the absence of historical precedence?

The question of whether or not it makes sense to ban specific types of developments depends on what the existing protocols for decision-making can deliver, in particular, methods of engaging stakeholders, formulating problems, assessing them and choosing issues for discussion and debate. In democratic secular societies, the legitimacy of particular decisions will have to be negotiated and renegotiated among those who are seen as stakeholders, bearing in mind that they always have agendas of their own. Conflicts over whether or not to ban or restrict developments of particular types of neurotechnologies will mainly stem from inadequate consultation or incompatible views. The typical candidates for banning include:

- Breaking the law
- Compromising individuals' control of their choices
- Too dangerous to one's health
- Breaching right to human dignity
- Breaching God's will

But the contentious issues may be less about particular types of developments and more about particular types of uses or configurations for how to apply neurotechnologies. For example, brain implants are an invasive and highly risky technology but the success in therapeutic settings invite speculations on the extent to which, for example, behavioural traits could be controlled with implants. These speculations push the boundaries of what counts as 'therapeutic purpose'. As it currently stands, brain implants in experimental and even the most stable variety is only permitted for therapeutic purposes for which no other method is available.

What we learn here is that the decisions to ban will typically rest on the risk of extreme scenarios resulting from implants failing in one or another way. The seat of implantation is the brain, a prioritised organ facilitating the person, identity and self-hood. The potential damages caused by an improperly implanted device or from procedural complications are far reaching and involve an unforeseeable deterioration of the person.

Robust regulation

Visions of the future have always had performative and rhetorical roles in technology

development, however, there is clear evidence of a ‘strategic turn’ in the latter half of the 20th century. Innovation policies and strategic research agendas are increasingly more explicit with promises and expectations that resonate the dominant social-cultural and political sentiment that science and technology will solve our individual and societal problems.

The perceived need for ethical reflection and understanding of morality presupposes conflict and requires dedication to questions of who is in conflict and whose values are at stake. Much less attention however, is devoted to the question of what the ethics ought to be ethics of. Ethics of technology tend to take the technology in question at face value, even if it does not yet exist except in scenarios of the future. The objects of reflection tend to be limited to potential impacts or outcomes for the lives and liberties of those who are likely to be affected or afflicted. Although 'downstream' engagement of this order helps to sort out deeply problematic issues of impacts and outcomes, it is inadequate in laying the foundations for robust ethical and policy frameworks.

Critical engagement with expectations and promises of visionaries and research leaders is lacking:

- How well are promises and expectations understood by policy-makers, ethical, legal and social expertise?
- How well are technically and operationally relevant matters understood?
- How are socio-technical imaginaries mobilised and new technologies constructed
- How well are the boundaries understood, between wishful enactment and what is actually possible?

Critical examination of the emerging new economies is lacking

- Which socio-economic assumptions can be said to underpin strategic research agendas and visionary work?
- Which socio-economic assumptions underpin recent innovation policies?
- What is the role of competitiveness as a value?

Institutionalised ethics are limited in engaging professional ethicists as well as publics:

- How are problems actually framed?
- Which issues are selected for reflection and debate?
- How can we overcome the shortcomings of presuppositions about rationality and agency that go into the construction of participants in debates, as 'the public', 'the citizen', 'the patient' the 'expert'?

Social-cultural innovations and endogenous behaviour change are largely overlooked

- How do attitudes, concerns and orientations change over time?
- What are the effects of behaviour change for organisational/institutional operations?

There are consequences here for ethics and regulation as a result of the perceived need for harmonisation. Cesagen’s work has included an exploration of the meaning of harmonisation and standardization in this context[11]. It can further be argued that attention should be devoted

11 Chadwick, R. and Strange, H. ‘Harmonisation and standardisation in ethics and governance: conceptual and practical challenges’, in H.Widdows and C.Mullen (eds) *The Governance of Genetic Information: Who Decides* (Cambridge, 2009) pp. 201-13.

to the politics of decision-making, innovation policy development, visionary work, the involvement of industries, and how new bodies of knowledge and operational expertises are constructed. Robust decision-making protocols will therefore need to ensure a balance of research with different focuses and aims:

- Downstream studies of potential impacts of the technologies that are already in the last stages of development and deployment (to minimise risks, maximise benefits and distributive justice, and improve wider acceptance)
- Upstream studies of imaginary impacts of technologies which may or may not be realizable (contribute alternative visions and scenarios of the future)
- Research into democratic negotiations of the very practices of envisioning and planning for future lifeworlds (contribute alternative futures).

Finally, policies and regulation on modifying performance or functions of the brain and peripheral nervous system ought to be informed by much better understanding of:

- Which experiential cultures are likely to find currency and which do not. (connecting nervous systems in gaming, artistic performance, sex?)
- To what extent are body modification artists willing to take their craft.
- To what extent are artists, like scientists, willing to self-experiment and set trends
- What unintended consequences have emerged from existing experimentations
- How are responsibilities managed in non-medical experimental scenarios.

Risks and benefits of neural stem cell therapy (Question 17)

The risks and benefits of neural stem cell therapy may not be well understood by either clinicians or the public (i.e. patients). It is a matter of some importance that patients & families actively seek out the clinics with links to potential transplant programmes, and many people will agree to anything in the hope of a cure or of a halt to disease progression. Patients told one Cesagen researcher that they would 'go for [stem cell therapy] without a minute's hesitation'.[12]

French and US literature on previous human neural grafts of foetal stem cells, shows variable results with lesions re-occurring in some transplanted areas, and/or lesions occurring in non grafted areas.[13] Hughes' ethnography of a research clinic found that this information was not

12 Hughes, J. 2010. *After genetics : Huntington's disease, local data, global neuroscience.* (PhD) Cardiff University.

13 Cicchetti, F., Saporta, S., Hauser, R. A., et al. (2009). Neural transplants in patients with Huntington's disease undergo disease-like neuronal degeneration. In *Proceedings of the National Academy of Sciences of the United States of America 106*. pp. 12483-8; Keene, C. D., Sonnen, A., Swanson, P. D., et al. (2007). Neural transplantation in Huntington disease - Long-term grafts in two patients. *Neurology* **68**(24). pp. 2093-8; Keene, C. D., Chang, R. C., Leverenz, J. B., et al. (2009). A patient with Huntington's disease and long-surviving fetal neural transplants that developed mass lesions. *Acta Neuropathol*. **117**(3). pp. 329-38.

always made readily available to patients.[14] Of course, this information may be irrelevant if the procedure is not available, and patients, families and the public can search on the web themselves (and they do). However, risks and benefits tend to be subsumed under one or more of the following type of provisos:

a) “We are not doing any transplants at the moment, and in any case we don't know if you would be a suitable candidate. It's likely that appropriate people would be in the early stages of disease.”

b) “It's a very experimental procedure and its too early to say what the chances are.”

c) “You are in the right place for when developments start to come through.”

So there is a tacit implication that research clinic attendance may prove to be beneficial even if only in terms of information, not treatment.

Ethical and social issues (Question 18)

The tissue from aborted foetal cells is black boxed - everyone (clinicians and patients alike) says 'stem cells', Hughes noted that no distinction was made in clinic interactions which discussed transplantation during her study.[15]

People with neurodegenerative diseases and their families are desperate for treatment and will take any risk to get it in most cases. They seek out those clinics they consider will give them an edge in being the 'first on the list'.

The patients may be losing cognition- and this is an important factor in terms of informed consent for any procedure. Patients in this position became very distressed when advised they cannot have stem cell transplants, even when transplant was not available. There is a certain amount of pathologising of this distress. If transplants were readily available, affected people may be even more distressed if not 'selected'. This type of distress is not often considered to be a 'medical harm', yet this can have a huge impact on families coping with the disease. It is not considered as a risk in the ethical framework of research programmes which are simply monitoring the patients' disease condition and gathering data.

It would be of value to conduct systematic ethnographic research on the understandings of tissue donors and potential patients as to any recognition of a special status accorded to tissue engineered brain tissue as opposed to other tissue types -- e.g. liver, kidney, skin etc in notions of identity and selfhood. The cell source mechanism may also be a variable here (iPS, hESC, neural tissue). In terms of autologous therapies, patient and patient family understandings of the processes applied to their own tissue, and the status of their own neural tissue in an in vitro context requires exploration. These issues remain pertinent in research processes prior to transplant via cell injection, for example the understandings of patient cell

14 Supra, n.11.
15 Supra, n.11.

donors whose neural tissue is being used as a model of disease, either In Vitro or transplanted into laboratory animals.

Non-medical uses of neuro stem cell therapy (Question 19)

This may prove extremely popular with the public and become a mark of status such as cosmetic surgery seems to be. Given that some people consider 'stem cells' to be a more 'natural' therapy[16], there may be fewer barriers to its adoption. However, will it create whole sections of society who have access to this and others who do not? Will it create a market for saviour embryo siblings for stem cell supplies? How does society decide what is human enhancement and what is not? What will be most affected - neurological functions, sport, physical body enhancement such as idealised male/female forms, fashionable/tribal forms in more severe ways than piercing or tattooing? A thorough public discussion is necessary about the pros and potential cons.

Regulating neural stem cell therapy (Question 20)

Since much of this research is being conducted with foetal material it would be of value to access the extent to which regulatory frameworks for sourcing foetal material from hospitals are standardised and transparent across the UK, along with how the tissue is transported back to (and kept in) the hospital where the surgical implantation will presumably take place.

Much of the current regulation appears to be in place on a paper trail in the run up to projects. There is also a long negotiation process from ethical approval to obtaining R & D approval. This is based on hypothetical situations in most cases and cannot cover every eventuality. It is often the case in research that situations arise which have not been considered - some form of speedy regulatory advice is vital. The continuing regulation of use of material relies on the integrity of scientists and operators of research, with further paper exercises such as audits. This is time consuming and potentially problematic for scientists and lab workers. But wider use of these technologies would mean more of the same. It would be good to have a regulatory system in operation which freed scientists from the tyranny of paperwork, but which also gave security to everyone i.e the users/developers of the neural material, the owners of the material, the surgeons and the patients who receive the material. This may be in the form of access to neural materials being licensed, limited or regulated in some way. This may happen already in one way or another. It may also need a new regulatory body. There does need to be a way to inspire and develop public confidence in the methods and uses of neural stem cells, and provide reassurance that the work is well managed for the public good.

16 Supra, n.11

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Appendix: Case Study

Technolife: Social imaginaries and ethical issues in deliberative process on Body and Mind Enhancement

This case study is comprised of extracts from a report that analyses an online public forum addressing ethical issues relating to questions of body and mind enhancement. The report is authored by Kristrún Gunnarsdóttir, Adrian MacKenzie and Brian Wynne, and it is one of Cesagen's contributions to the FP7-funded research project, Technolife (Contract No: FP7-230381) – http://neicts.lancs.ac.uk/technolife-wp4.htm. The extracts were written by Kristrún Gunnarsdóttir.

Introduction

This deliverable reports on the analysis of a virtual forum discussing body and mind enhancement. The forum was facilitated by KerTechno (see D3.1)[17], and invitations were extended to a number of individuals and groups who are considered stakeholders of one or another kind: experts, administrators, relevant occupations, interest groups, and more (see D2.0)[18]. Discussions were kick-started with a short provocative film[19], drawing on a scoping exercise attempting to capture the 'hot topics' engendered by body and mind enhancement technologies. The scoping paper (D1.3)[20] identifies an increasing preoccupation with issues of immortality and a juxtaposition of a world of bodies with virtual existence and identities. The scoping paper also explores scenarios, depicting efforts of overcoming imperfections, ailments, shortcomings and finitude. They disclose a future world of more capable, healthier and longer lasting bodies and minds, even *super-soldiers* and *super-intelligence* (see e.g. Roco and Bainbridge, 2002)[21]. Science fiction has for a long time played a major role in cultivating such visions where body and mind enhancement is speculated on, but also tried and tested as indicated by recent developments in the use of implants or by latest advances in bionics and reconstructive surgery.

Particular complications arise against the emergence of transhumanism (e.g. Bostrom, 2005)[22]. Techno-scientific utopias, such as Ray Kurzweil's notion of *Singularity*, scenarios of leaving the body behind for virtual existence in cyberspace, and new body cultures that fetishise modification (tattoo, fitness, fashion, implants and cosmetic surgery), are all ethically and substantively challenging. The virtual existence of a person is a digital 'placeholder', perfection is an unstable category, and whether or not quality of life can be improved upon remains an empirical matter. Many existing enhancement technologies are experimental with uncertain and unpredictable results. And, apart from potential physical complications, there are issues regarding changes in emotion, personality and identity, and a risk of deep disappointment.

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A controversial film?

If the short provocative film “was intended to be controversial”, as Bryan [forum participant] puts it (D4.3.8, line 2), one has to ask how exactly it is controversial with reference to the direct responses we observe. For example, we observe overwhelming optimism and a positive disposition regarding the potential of body and mind enhancement. “I think it will be quite natural” (D4.3.5, line 5), “technological developments will almost certainly make it possible for human beings to live really longer and in better health” (D4.3.6, lines 5-6). In other words, “very beneficial for […] people [… and] for society at large” (D4.3.6, lines 13 and 16-17). A significant incentive here is improved life quality and life expectancy with 'spare part' replacements and modifications of the body, including the brain. The narrator in the film offers [*t*]*otal freedom, freedom of movement, freedom of morphology, freedom of choice*. According to contributors who indicate they feel that people should have those freedoms, the freedoms appear to be conceived of as possession or 'right'. It is noteworthy in this respect how substantive challenges to common medical treatments typically signal lack of freedom and choice in light of physical/material complications, often followed by disappointment and frustration. Justification for treatment (or enhancement) on the basis of improved life-quality needs matching against the contractual complexity of entering treatment, and questions are inevitably raised about the voluntariness of subjects and others involved. That said, it remains obscure if participants' imaginaries on future bodies and minds are science fiction or possibly deemed to be of techno-scientific credibility.

Direct evidence, showing that the film raised alarm among participants, centres on three issue clusters. The first cluster concerns the uses of the term 'perfection' and, by proxy, the terms 'normal' and 'natural'. Participants either latch onto these terms uncritically or they are very sceptical and find “the concept of 'perfection' misleading” (D4.3.1, line 2). The quest for perfection “is like the quest for wealth […] it is never enough” (D4.3.2, lines 2-3), and the term is used “as if it were possible to somehow reach an ultimate goal” (D4.3.3, lines 5-6). The second cluster concerns critiques of consumer/mass-market exploitation. Beth [forum participant] is particularly opposed to representations of enhancement technologies as if they were new gadgets for mass consumption. Although, it might be perfectly reasonable to expect new technologies to develop in a market democracy, the juxtaposition of mass-marketable enhancement products versus personalized products and services, indicates that there are different ways in which the new developments could go forward. Finally, the third cluster of questions turns on why we might want these developments, who has access to them, who can pay or who is willing to pay.

Taken together, these immediate responses to the film set the tone for further discussion and debate that addressed more directly the suggested focus topics of the forum, i.e., on *perfection*, *freedom of choice* and the question of *humans becoming cyborgs*. For example, discussing the quest for perfection has already foregrounded issues of social and ethical relevance, with reference to social-cultural versus objective 'perfection'. Normative indicators of perfection such as happy, healthy and beautiful are also subject to doubt and some confusion. The topic of having freedom to choose one's body and mind is also hinting at social pressures to conform to certain body and mind types, as opposed to the possibility that enhancement will bring about new and unexpected configurations of humans. One could

argue that the reference in the short film to the Nazi agenda of 'perfect' bodies and minds, without pain or limits, would encourage discussion along those lines of conformity versus choice, however, the only direct response to that scene called the comparison with current discourse on body and mind enhancement ridiculous. But, we see a macro-proposition emerge, telling us that, *body and mind enhancement is inevitable and will create previously unknown varieties so we should prepare for a widening range of human capabilities*. Finally, between two participants, Ben and Bart (D4.3.9), still another proposition emerges, telling us that, *the future will unfold in ways we may or may not like, but if we cultivate a sense of ethics and morality, 'professional ethics' will be redundant*.

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Addressing the topics: Issues of ethical and social relevance taking shape

. . . . As these discussions on perfection and desire for improvement progress, we notice how participants touch on questions of haves and have-nots, visions of scarcity and post-scarcity, and the role of capitalism in creating the need (greed) and strive for perfection, superiority, and so on. One view we observe states that dystopian scenarios of haves and have-nots are crafted to artificially generate moral conversations, utilising new technologies to discuss ethics along economic class lines and in ways that seek to guarantee moral outrage at the ruling class. But some of our participants are deeply concerned about enhancement technologies progressing under the dominant socio-economic and political conditions in Western countries where the ruling classes cannot be trusted. One participant also suggests that perhaps we are seeking to overcome body and mind imperfections which are merely the symptoms of imperfect situations, namely, the radical product/consumer agendas of contemporary societies. Finally, these discussions point out the unequal and unfair distributions of good and bad qualities already, i.e., neither *nature* nor *nurture* are equal and fair, and the question is raised, whether we maintain these differences by striving for a state of perfection. In other words, the world is already unfair and enhancements can possibly turn that around, keep it much the same or exacerbate it.

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Participants also begin to differentiate between therapy and enhancement in their discussions on freedom of choice. They raise the issue of sickness and death as naturally integral and essential to our existence, and one participant asks explicitly why we push these factors as far away as possible from our lives. These and similar sentiments draw attention to questions of 'naturalness' of the variety of experiences and existential ills we are ordinarily faced with. As some participants emphasise, we might have misconceived ideas about perfecting imperfections, like our susceptibilities to a range of common diseases which perhaps are simply the consequences of environmental/societal problems. Such imperfections would go away if everyone had clean air and water, enough space, naturally cultivated foods, access to basic medicine, and so on. However, chances are that we choose enhancements that cannot change our societies, only deepen already entrenched societal and environmental problems. This is perhaps most starkly illustrated in the view that is useless to deliberate the 'goodness' of supreme health and enhanced intelligence because these are self-evidently good and the choices *should* be accessible to everybody. As some of our participants point out, accessibility for *everyone* is not the kind of world we live in.

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The question of whether living longer and staying beautiful will lead to super-humans or cyborgs, affords a number of speculations. First we observe that participants consider the question of 'normal' as gradually changing its meaning to connote, living as one pleases, looking and acting which ever way one chooses. In other words, 'normal' will assume 'variety', possibly transcending conventional notions of beauty or perfection. Whether the future holds biological or digital varieties in store is left by participants as an open question. They engage in deliberations on the possibility of developing digital personalities and going viral, of a future of regenerative medicine, molecular-scale tools, and the possibility of integrating artificial systems into the body. One view we observe is that enhancement technologies are considered to be like any other assistive technology. The boundaries of what counts as invasive are blurred and different technologies sit on a continuum, say, from eye glasses, to contact lenses, to laser corrective surgery, to the bionic eye. Here we see again how enhancement is placed on a continuum with treatment, however, participants do not agree. Another view is that distinctly invasive measures are disruptive in the sense that we will most certainly see permanent irreversible alterations of humans and our socio-technical systems. The question is asked if we can be in control of such radical alterations, but also why not to take our destiny into our own hands to go with it.

A substantial development in this discussion pertains to arguments which are highly critical of the dominant socio-economic and political conditions. Technological advancements are currently a proprietary business but the core of this critique seems to spur the idea that advancements will ultimately enable utopian conditions—a world in which there is no scarcity and only minimal if any cost of obtaining tools/devices or basic necessities. The model for this utopia is primarily the success of open-source software, the changing computing capacity-price ratio over the years and the spread of mobile, smart, and personal computing to all corners of the world. Computing is also the reference point for believing in a future of converging nano, bio, information and cognitive technologies, involving nano factories, self-replicating mechanisms and more. One of the consequences of this computing analogy is the perception that biotechnology will shift from generalised mass-marketable products, a way from big corporate enterprise, toward personalized technologies, open-to-all recipes in a highly participation-based model, similar to how the open-source communities work. Biotechnology will not need ivory towers but passionate individuals who can both learn and contribute, for example, to bio-informatics, genomics and proteomics. We could reach a society of naturally evolving experts in everything—a future of automated virtual tools for lay persons to design organisms or a future where tasks currently done in big laboratories, can be accomplished by 2-3 graduate students. Such a development would counter the current 'competitive edge' aspect of enhancement technologies. But another implication of this analogy for the future of human bodies and minds, is that computing is on the brink of being internalised completely into our practices. It will eventually transcend all previous distinctions of user-groups, categories and classifications and create an oracle which will be intelligent in its own right. One enhancement is to be super-connected, another to be filled with cutting edge smart body and/or brain implants, still another to be 'uploaded' into the super-connected system.

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Ethics of body and mind enhancements

As we point out in the introduction to this report, the scoping exercise identifies preoccupation with immortality and convergence of the virtual, mental and physical. We learn that science fiction has played a major role in cultivating visions of body and mind enhancements while recent developments in the use of implants and advances in bionics give some idea of what the implications might be of using such technologies to enhance humans. We also learn that techno-scientific utopias that fetishise modifications or speculate on leaving the body behind for virtual existence in cyberspace, give us some idea of what we expect, hope or fear the future might look like.

Techno-scientific realities, science fiction and techno-scientific utopias are not well distinguished in the forum and this obscurity draws together our key observation, *idealistic imaginaries*, whether or not our participants are optimistic, sceptical or fearful about body and mind enhancements. One can argue, with good reason, that imaginaries are just that. There are no limits to what can be conceived of and depicted as a socio-technical imaginary because an imaginary lacks the friction of actual socio-technicalities. For example, there is consistent lack of association with the complexities of entering any kind of substantial medical treatment and being the *body-in-treatment*—the pain, the side-effects, delays in recovery, long-term effects, and the possibility of *never being the same again* and, consequently, one's life never the same again either. Becoming an 'other' in that way, does not represent the kind of imagined modifications our participants discuss and debate.

What we also observe is how the forum is almost exclusively concentrated on enhancements as such, in the sense that modifications of bodies and minds which would normally not be seen as enhancement, are omitted from the discussion. One can argue that the social semiotics of the film persistently draw the attention away from *modification-as-experience*, while pushing an agenda of enhancements for the practical purposes of being *happy*, *healthy*, *beautiful* and *forever young*, along with stereotyped manifestations of those qualities. We argue that this is indeed a shortcoming, for example, considering the lengths to which participants express their sentiments toward dominant socio-cultural conditions and orientations. Namely, a considerable development in recent decades concerns the 'experience economy' –an area of significant cultural currency whereby *new experiences* are marketed through personalized services and products. In this respect, it would be a legitimate question to ask to what extent body modification artists can take their craft, implanting 'smart' objects into bodies, and how popular such practices could become and what the implications of that might be.

However, in spite of any shortcomings in the orientation of discussion topics in our forum, we observe how thinking about the future of humans, cast in terms of body and mind enhancement, serves as a screen upon which we collectively project depictions of ourselves as individuals, our place in the world and relationship with each other and with progress, for better or worse. Participants produce a number of projections of this order in communicating the quest for perfection (including super-bodies and super-intelligence), the inevitability of progress through exponential growth in techno-scientific advancement, the role and viability of the dominant socio-economic system, and the journey ahead towards a new world order. We already observe this in responses to the film, producing these propositions:

- Perfection is untenable, an endless and flawed quest, and a lie to exploit consumer behaviours to market it.
- Body and mind enhancement is inevitable and will create previously unknown varieties so we should prepare for a widening range of human capabilities.
- The future will unfold in ways we may or may not like, but if we cultivate a sense of ethics and morality, 'professional ethics' will be redundant.

We further observe the emergence of propositions such as:

- People will not want the same for themselves as everyone else. They want to be unique and innovative.
- Enhancements should never be one-size-fits-all in case of a biological or digital attack
- It is useless to debate the 'goodness' of supreme health and enhanced intelligence. These qualities are self-evidently good.
- Neither nature nor nurture are fair in their distribution of qualities. Enhancements can turn that around, keep it much the same or exacerbate it.

We also observe propositions with which participants position themselves in their discussions, for example, there are *progressives* and *luddites*. But overall, our participants produce a wide range of projections of how the betterment of ourselves and the world at large, could be improved with technology, not in terms of productivity or efficiency, but enjoying life, better understanding of the world, helping humanity progress, and so on. Serious and tragic consequences are made clear as well to some extent. What stands out however, is the projection of a new world order, anticipating the emergence of open-source biotechnology. These utopian conditions depict a world of no scarcity and only minimal cost of tools/devices or basic necessities—a future of converging nano, bio, information and cognitive technologies, involving nano factories, self-replicating mechanisms and computing that transcends all previous obstacles so we can be super-connected, filled with cutting edge smart body and/or brain implants.

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