RESPONSE TO NUFFIELD COUNCIL ON BIOETHICS CALL FOR EVIDENCE – NEUROTECHNOLOGY

The following submission has been prepared by Dr Louise Hatherall and Professor Muireann Quigley from the Birmingham Law School at University of Birmingham in response to a request for evidence form the Nuffield Council on Bioethics. The evidence is drawn from empirical findings for the Everyday Cyborgs 2.0: Law's Boundary-work and Alternative Legal Futures project.

The Everyday Cyborgs project explores the legal implications where persons are joined with (increasingly 'smart') implanted and attached medical devices. It also seeks to understand the different legal futures that 'everyday cyborgs' (that is, persons with attached and implanted medical devices) might imagine, and the legal and regulatory changes needed to achieve these futures. The project focuses on medical devices broadly conceived, rather than neurotechnologies specifically, and so the response is informed, and necessarily limited, by this. The (users of) technologies represented in our response below, include cochlear implants, pacemakers, lower limb prostheses, and insulin pumps.

Our response focuses on two aspects outlined in the call for evidence: (1) the question of how surgical implants, prostheses or non-biological devices, used for therapeutic purposes, affect individuals' or communities' sense of identity; and (2) the request for case studies, data, or other examples about patients undertaking self-maintenance or DIY modification of their own neurotechnologies for any reason.

A. Executive Summary

A.1 Identity and Medical devices

1. Our interview findings suggest that effects on individual identity from receiving/using a medical device are not universally shared.

2. Whilst most of our participants reported some impact on their sense of identity, the ways in which this manifested varied.

3. Others reported ambiguity about the relationship between identity and device, whilst some were clear that there was no impact at all.

4. The relationship between identity and devices can be dynamic and can change over time.

A.2 Case Studies of DIY Device Modifications

5. A principal driver towards DIY solutions is dissatisfaction with the performance and/or functionality of their existing devices.

6. Modifying devices enabled participant control, which was reported as not just important in-and-of itself but as vital for enabling them to better navigate their day-to-day lives.

A.3 Capturing Empirical Perspectives

7. A deeper interrogation of existing empirical literature conducted with device users will likely be needed to capture further ethical, legal, social, and practical impacts of neurotechnologies.

B. Impact of Medical Devices on Individual Sense of Identity

Our interview findings suggest that there is no one-way in which medical devices affect an individual's sense of identity. Some viewed the impact as positive: facilitating their identity in ways which were not possible prior to receiving the device. Others reported negative impacts; namely, (1) the (in)ability to express their identity through aesthetic choices and (2) limiting or (mis)shaping their career choices. Not everyone agreed that their devices impacted their identity at all: some responses suggest ambiguity in the relationship between the two, or no discernible impact. What was clear from our findings was that the relationship between devices and identity is not static, but dynamic and shifting over time.

B.1 Positive and Negative Impacts on Individual Identity

Some participants reported that their devices did impact on their identity, but this manifested in myriad ways. For some, the devices did not change their identity but enabled individuals to be authentically themselves. One participant summarised this neatly, commenting that:

> "I took early retirement and then…I had the [cochlear] implant, which turned my life around totally and enabled me to be much more the person that I am, rather than up to then being the person that I had to be because I couldn't do so many things".

Another participant, an OS AID system user, reported a sense of completeness arising from the use of the device:

> "In a large way it's like well I don't have the eyelet cells, so I have this robot instead and now I am a whole person… whereas before it was like taking this medicine because part of me doesn't work right".

Others reported a negative relationship between their identity and device. Some participants recounted how using their medical devices limited the ways in which they could express themselves, impacting their sense of identity. A participant with a lower limb prosthesis discussed how their clothing choice – an important way in which they conveyed their identity – was disrupted: "I couldn't wear the same clothes anymore because I couldn't wear heels…my wardrobe for the last five years has been dictated by what the leg needs".

Another participant, a hearing aid user, noted the impact of the lack of aesthetic choices for their device:

> “One of the biggest frustrations I’ve had with hearing aids over the years is…As soon as you turn 16, you have beige hearing aids and that’s it. I have to fight to have something a different colour…So I’m up for a blue or [a] bright green colour, because I like to think of myself as a bright interesting person. I’m not beige and horrible yellow.”

There were, however, examples of participants finding ways to express themselves despite these limitations. One interviewee explained how they bought a wrap for their prosthetic leg, which was covered in expletives, commenting: “I want the leg to reflect that, and who I am and I am quite sweary.” Similarly, a cochlear implant user discussed how they would decorate the wire which connects the sound processing unit on their ear, to the transmitting coil which is attached to their head with charms.

Other ways participants reported losses of identity were harder to overcome. Interviewees recounted job losses because of device use or shared that they had changed careers to more easily live life with their device. One participant, a user of Bone Anchored Hearing Aids (BAHA), for example, had multiple career commitments which required extensive, frequent meetings. They suffered with hearing fatigue (a common reported impact of BAHA), eventually suffered burn out, and changed jobs. For others, the devices meant that they lost a sense of what their future careers or identity could be. One participant discussed letting go of a dream of flying:

> “Yeah, I mean look when I was a child, I had dreams of becoming a pilot for example. And even now it’s, if I want to get just a private pilot’s licence, fees aside, that there are limitations to what I’m allowed to do independently, right.”

Finally, others felt that their device gave them a new identity which represented the integration of themselves with technology. Some (but not all) of our participants embraced the label of ‘robot’, ‘bionic’ or ‘cyborg’ to describe themselves. As one participant noted:

> "I'm an everyday cyborg, I'm not going to try and hide the fact that this is what I am, in fact I'm going to make the most of it that I possibly can because why not? It's fun, it's interesting and this item that I'm wearing, it's as unique as I am, you're not going to find another thing like me or another thing like this."

B.2 Ambiguous or No Impact on Individual Identity

There was some evidence in the interviews which suggests ambiguity surrounding the relationship between the user's sense of identity and use of their device. Another user of cochlear implants observed that "you'll always be the same person whatever…In some ways it's changed my trajectory in life, but has it changed me, I don't know."

Some felt that devices did not impact their sense of identity because they were no different from other, less frequently commented upon, medical devices such as eyeglasses. Related to this, some participants observed that most people are integrated with technology to varying extents (through, for example, reliance on mobile phones) and that medical devices were therefore no different.

B.3 The Dynamic Nature of the Relationship Between Device and Individual Identity

What was clear from the interviews, was that the relationship between identity and devices was not static, but dynamic. The relationship might change depending on the how well the device functioned, as one user notes:

> "Your independence, your confidence, well everything, it just feeds, it trickles into everything. And you get to a stage where you love your prosthetic, it fits, you start getting out and about again and then it doesn't fit and you're off your limb and it's that rollercoaster."

Another user reported that the use of OS AID technology shifted their perception of themselves as a person with diabetes, commenting that: "The other day I met up with some old friends from school, and I mentioned in conversation that I felt less diabetic now." Additionally, a user of hearing aids felt that as they aged and developed so did their audiology graph, which became a projection of their own personality.

C. Case Studies: Self-Maintenance or DIY Modification of Devices

C.1 Programming Hearing Aids / Cochlear Implants

One participant recounted their experience of programming the software for their hearing aids. An electrical engineer, they were frustrated by the poor performance of the device and felt that healthcare professionals lacked the skills to appropriately programme their hearing aids for optimal performance. This frustration was compounded by a limited understanding of their lived experiences as someone with profound hearing loss. Discussing an appointment to programme their hearing aids, they recalled:

> "The question is 'what does that sound like?' You know, 'what did this sound like?' Now you've got no words: how am I supposed to reply when I've never heard a word?"

Wanting more control over their hearing, the participant programmed their own device, buying third-party equipment to do so. This successfully improved their hearing and – despite going against user agreements about the use of their device – they were supported by both the hospital and device manufacturer which the participant described as "a wonderful place to be in".

The same participant eventually received cochlear implants (to treat ongoing tinnitus), and they were eager to programme the implants themselves and to retain the control over their hearing they had achieved with their hearing aids: "That was my key question because I don't want to lose control when I've fought so hard to get it."

Unfortunately, this was not possible, and they reported similar complaints to programming their hearing aids. Yearly check-ups merely ascertained whether the device was working appropriately, but did not aim to improve the hearing settings. Eventually, they attended an ENT appointment with an engineer who had previously worked for a cochlear implant manufacturer, which transformed their hearing. The participant emphasised that the engineer listened to them and did not see "good enough" hearing as sufficient, but as something improvable. For this participant, this emphasised the need for more control over the programming of their device, and for hearing mapping to be conducted by those with expertise:

> “I’m kind of angry: why did I have to endure [the poorer hearing], why couldn’t I check? I’m not stupid. He’s not going to stay there forever. He’s too good. So then how do I prepare for that…so we need good people in control of the maps.”

C.2 Open-source Automated Insulin Delivery Systems

Whilst not a neurotechnology, several of our participants were users of OS AID systems. This system creates an ‘artificial pancreas’ where open-source software (installed on a small computer or a smartphone) connects a person’s continuous glucose monitor (CGM) to their insulin pump, enabling insulin delivery to be adjusted automatically and in (near) real-time. OS AID systems have been developed by members of the diabetes community in response to dissatisfaction with existing methods of diabetes treatment, which were viewed as complex, cumbersome, and burdensome.

These systems have been in use globally for over 10 years, and before any comparable regulator-approved, commercial systems were available. In the UK, for example, NICE only recommended the use of regulated commercial equivalents at the end of 2023.[1] Despite this access to the available commercial systems is still not straightforward and is subject to, for example, a 5-year rollout plan by NHS England.[2] All interviews took place before this recent recommendation from NICE.

All participants we spoke to experienced success using one of the available OS systems (e.g. OpenAPS or AndroidAPS). For some, the impact of this is hard to overstate: one participant described that the quality-of-life impact of using the device as “revolutionary”. The participants we spoke with who use the systems report mixed responses from their healthcare team about the use of OS AID. Some reported that their healthcare providers were hesitant to discuss use of the systems with them, whereas others discussed it openly as a potential option for diabetes management. Discussing a move to an OS AID system, one participant noted:

> “My diabetes team were very supportive, because they were the ones who came up with the idea of putting me on the [CGM] and I think they’re quite keen to get their patients with as much kit as they want…And I know it hasn’t been the case for all diabetes teams, including ones that I’ve been with.”

Users reported multiple benefits of these systems, including improved control over their blood glucose with less mental labour involved in managing their diabetes. There was an associated decrease in stress doing so, as one participant noted:

> “I think it’s improved my control, but probably one of the main benefits, which I wasn’t particularly expecting, is just that there is just much less mental effort. It means that I don’t have to, or maybe not that I don’t have to, but I don’t stress about what’s going on at any given moment.”

Importantly, even though it was technically a do-it-yourself system, there was a community of support around them. These included extensive documentation on how to set-up and run the systems, in-person meet ups, and online community forums for troubleshooting and to discuss managing the systems and devices. Participants also reported benefits which flowed from being able to easily adjust the settings on their devices to take into account their daily activities. One participant, a keen gardener, observed:

> “I can go out in the garden and if I’ve got it set up right, so if I’m running I’ll drop my profile to 50%, so my basal rate and my sensitivities and everything just get cut back and set my target blood sugar level to a higher level and then if I do that in adequate time it sorts itself out…. And I just can keep going, whereas previously I’d go for maybe an hour and a half [and then] have to come inside.”

Some participants felt that being able to adjust their settings was not just desirable, but a right that they were entitled to. Discussing access to the data generated by OS AID devices, one participant commented that:

> “[the settings] gets adjusted over time and I very much take ownership of those too. I think I have the right to change those. If I am feeling stressed, I should be able to up my basal rate or whatever.”

These case studies demonstrate that continued access is not the only reason people turn to self-modification or DIY options. In our examples, participants felt that their quality of life could be better than what their previous devices allowed and so turned to solutions beyond the healthcare system to achieve the outcomes they desired.

These case studies also show the importance of user control over their devices. The ability to adjust settings to facilitate their day-to-day activities was vital for both the hearing aid / cochlear implant user, and those who used OS AID systems.

D. Capturing Empirical Perspectives

The data gathered for the EDC project is a modest sample size and captures a wider range of device users than just neurotechnologies. A deeper interrogation of existing empirical literature is likely needed to further elucidate ethical, legal, and social issues relating to neurotechnologies. Whilst the associated literature review to this call for evidence captures a range of evidence, it does not yet reflect the range of empirical evidence which exists across the socio-legal and social sciences disciplines, specifically that directed at capturing device user perspectives. This may, in part, be a limitation of the databases used to identify relevant literature (JSTOR and Westlaw). Targeting databases which have a broader range of socio-legal and social science literature (such as SCOPUS) may aid in identifying related and relevant research.

E. Summary

In conclusion, this research indicates that the relationship between an individual’s sense of identity and use of medical devices is diverse, dynamic, and can shift over time. Two reported case studies - (1) programming hearing aids/cochlear implants and (2) open-source automated insulin delivery systems/DIY artificial pancreas systems – show that users were driven to DIY solutions by dissatisfaction with the performance or function of their devices. These solutions have, for our participants, been largely successful. Modifying devices gave users control over their technology and their health and has enabled them to better navigate their day-to-day lives.

F. References

[1] National Institute for Health and Care Excellence 'Hybrid Closed Loop Systems for Managing Blood Glucose Levels in Type 1 Diabetes', 19th December 2023. https://www.nice.org.uk/guidance/ta943/chapter/1-Recommendations, accessed 4th February 2025.

[2] NHS England, 'Hybrid Closed Loop Technologies: 5-year Implementation Strategy', 22nd January 2024. https://www.england.nhs.uk/long-read/hybrid-closed-loop-technologies-5-year-implementation-strategy/, accessed 4th February 2025.

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More information about the Everyday Cyborgs 2.0 project can be found here: https://blog.bham.ac.uk/everydaycyborgs/ or by contacting us on everydaycyborgs@contacts.bham.ac.uk.

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