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Disability and Rehabilitation: Assistive Technology

ISSN: 1748-3107 (Print) 1748-3115 (Online) Journal homepage: www.tandfonline.com/journals/iidt20

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To cite this article: Odile C. van Stuijvenberg, Katherine Bassil, Marike L. D. Broekman, Annelien L. Bredenoord, Johan H. M. Frijns & Karin R. Jongsma (26 Sep 2025): AI-driven neural implants for vision and hearing: a qualitative study of user perspectives, Disability and Rehabilitation: Assistive Technology, DOI: 10.1080/17483107.2025.2559188

To link to this article: https://doi.org/10.1080/17483107.2025.2559188

DISABILITY AND REHABILITATION: ASSISTIVE TECHNOLOGY
https://doi.org/10.1080/17483107.2025.2559188

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AI-driven neural implants for vision and hearing: a qualitative study of user perspectives

Odile C. van Stuijvenberg[a], Katherine Bassil[a], Marike L. D. Broekman[b,c], Annelien L. Bredenoord[d], Johan H. M. Frijns[e,f] and Karin R. Jongsma[a]

[a]Department of Bioethics and Health Humanities, Julius Center, University Medical Center Utrecht, Utrecht University, Utrecht, The Netherlands; [b]Department of Neurosurgery, Haaglanden Medical Center, The Hague, The Netherlands; [c]Department of Neurosurgery, Leiden University Medical Center, Leiden, The Netherlands; [d]Erasmus School of Philosophy, Erasmus University Rotterdam, Rotterdam, The Netherlands; [e]Otorhinolaryngology and Head and Neck Surgery, Leiden University Medical Center, Leiden, the Netherlands; [f]Leiden Institute for Brain and Cognition, Leiden, the Netherlands

ABSTRACT

Neural implants are being developed to treat various conditions, including sensory impairments such as blindness and deafness. In these technologies there is a growing role for artificial intelligence (AI) to enable interpretation of complex data input. Current users of cochlear implants (CIs) face challenges in noisy environments, prompting the development of AI-driven software for personalized and context-aware noise suppression and speech enhancement. For blindness, an AI-driven cortical visual neural implant (cVNI) for artificial visual perception is under development. Here, AI-driven software may be used to process camera imaging for interfacing with the brain. If successful, these devices can offer important advantages for their users yet may also have ethical implications. Perspectives of (potential) users of these technologies is an important source for ethical analysis, yet so far these have not been explored in-depth. We performed a focus-group and interview study including potential users of a) the AI-driven cVNI ($n=5$) and of b) the AI-driven CI ($n=3$), and c) current or (former) users or a retinal implant ($n=3$). Focus groups and interviews were transcribed and analyzed thematically. Perspectives were clustered under 1) expectations and experiences, including improvements from the status quo, enhancement of autonomy and design requirements, and 2) perceived risks and anticipated disadvantages, including uncertainty on effectiveness, operational risks, surgical risks, and media attention. AI-driven neural implants for vision and hearing were positively received by potential users due to their potential to improve autonomy. Yet, possible conditions for uptake were identified, including device aesthetics and sufficient levels of user-control.

➢ IMPLICATIONS FOR REHABILITATION

- Perspectives of (potential) users of AI-driven sensory neural implants are an important source for ethical analysis of these technologies and should be considered in their development.
- AI-driven sensory neural implants are expected to enhance autonomy of users by increasing functional independence in AI-driven cVNI users and improving accessibility of noisy environments in AI-driven CI users, also reducing social isolation.
- AI-driven sensory neural implants raised some concerns on risks in case of cortical implantation, reduced user-control in case of use predictive functions, and anticipated media-attention.
- Design of AI-driven sensory neural implants should aim for high levels of usability, and the need for consideration of aesthetics in development of the cVNI was emphasized.

ARTICLE HISTORY
Received 15 May 2024
Revised 21 August 2025
Accepted 4 September 2025

KEYWORDS
Ethics; neurotechnology; implants; artificial intelligence; sensory implants; visual implants; cochlear implants

CONTACT Odile van Stuijvenberg o.c.vanstuijvenberg-2@umcutrecht.nl University Medical Center Utrecht, PO Box 85500, 3508 CA Utrecht.

Supplemental data for this article can be accessed online at https://doi.org/10.1080/17483107.2025.2559188.

Introduction

The field of neural implanted devices is fast-growing, and applications of artificial intelligence (AI) in neurotechnology are expected to increase [1,2]. Examples of such neurotechnology currently under development are AI-driven neural implants for vision and hearing.

Over the past decades, a few types of visual neural implants (VNI), including both cortical as well as retinal implants, have been under development to restore visual function in blind individuals by generating artificial visual perception [3,4]. Experimental research has shown that the application of weak electrical stimulation to the retina or visual cortex by an implanted electrode array can induce the perception of "phosphenes", artificial dot-like visual percepts (for an overview see Chen et al. [5]). The perception of phosphenes through retinal implants requires users to have an intact optic nerve, a condition not met by all blind individuals. The implantation of a VNI directly in the visual cortex overcomes this limitation.

An early example of a cortical implant is the Dobelle implant, which was implanted in a (known) total of 21 blind volunteers between the 1970s and 2005, showing some initial success in terms of phosphene perception [6–9]. Recently, a new cortical VNI (cVNI) has been under development [5]. This cVNI aims to generate artificial visual percepts in the user through stimulation of a large number of intracortical electrodes in a 1024-channel implant in the visual cortex. This implanted component is combined with a camera and an AI-software processor, both carried by the user, allowing visual information recorded by the camera to be wirelessly converted to electrical stimulation of the visual cortex to construct a visual perception based on multiple phosphenes [5]. However, before future clinical use, feasible improvements in device biocompatibility and/or refinement of implantation techniques are needed [10].

While cVNIs still remain largely in experimental phases of development, the Argus II Retinal Prosthesis System received FDA approval in 2013. However, this device was discontinued by the manufacturer Second Sight because of financial reasons in 2019 [3,11]. In the Argus II retinal implant, camera images could be converted using several (non-AI based) image processing algorithms, following which visual percepts based on phosphenes were induced through direct stimulation of the inner retina via a 60-channel microelectrode epiretinal array, replacing the function of degenerated photoreceptors [12].

Cochlear implants (CIs) for the treatment of severe to profound hearing loss are a more established and well-known type of sensory implant. CIs have been widely used for decades; in July 2022 more than one million registered CIs had been implanted worldwide [13]. A CI generally consists of an internal component surgically implanted in the cochlea, and an external component that serves as a microphone and sound processor. The external sound processor encodes surrounding sound to a coded electrical signal, which is transmitted to the CI's internal component through transcutaneous radiofrequency coupling. The internal component includes a subcutaneous radiofrequency receiver coil, which receives these coded signals, and relays this signal to the multichannel electrode array in the cochlea. This electrode array bypasses damages sensory hair cells and directly stimulates the cochlear nerve to generate artificial hearing [14].

CIs perform effectively in quiet environments; however, there is evidence that speech understanding in noisy environments is an ongoing challenge for CI users, especially when they are expected to actively participate in academic or professional settings [15,16]. These challenges might result in persistent stress, fatigue, and isolation from the community [16,17]. To address these issues and to improve the listening experience of CI users, AI technology is currently being developed aiming for personalized and context-aware noise suppression and speech enhancement in CI speech processors. These novel machine learning techniques are being developed with the aim to optimize the signal, perform auditory scene analysis, and combine binaural signals to enhance speech understanding in noisy environments and to follow target voices in complex scenes, this way aiming to impact the overall sound and its perceived quality.

Though the AI-driven cVNI and AI-driven CI offer important opportunities for therapeutic advancements for patients, these technologies also give rise to ethical questions. To date, several ethical implications of VNIs have been described in the academic literature, relating to themes like benefits for health and well-being, harm and risk, autonomy, societal effects, clinical research, regulation and governance, and involvement of experts, patients and the public [18]. Yet, empirical data on patient perspectives is

lacking [18,19]. Lane et al. [19] emphasize that considering the primary aim of these devices is to enhance the quality of life, it is essential to engage patients to capture their real-life experiences. Ethical implications of CIs have been widely discussed in scholarly debate, covering, among others, the ethics of implantation in young (incompetent) children and the disability interpretation of deafness and Deaf Culture [20–22]. In contrast to VNIs, there is a broader body of empirical studies on current CIs, including both studies with adult (potential) users and parents of hearing-impaired children [23–28]. Yet, none of these studies specifically address the potential use of AI technology in cochlear implants, even though the use of AI in neurotechnology has been proposed to raise concerns on privacy and consent, agency and identity, augmentation and bias [2].

This empirical study follows the Ethics Parallel Research (EPR) approach to provide ethical guidance for the responsible development of technologies, by taking on a role as embedded ethicists, closely collaborating with developers and (prospective) users of these technologies. Therefore, we aim to explore the perspectives of potential users of the AI-driven cVNI, former and current user(s) of a retinal implant, and potential users of the AI-driven CI (i.e., users of current CIs) to identify ethically relevant considerations regarding the development and use of these technologies [29].

Methods

Study design

To explore the perspectives of former, current and potential users of VNIs and CIs on AI-driven neural implants for vision and hearing, we conducted a qualitative study consisting of focus groups and individual interviews. Focus groups are semi-structured group discussions in which a specific set of topics is explored among 4–12 people [30]. Study methods and results are presented in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [30]. The Research Ethics Committee of University Medical Center Utrecht determined that the study (research proposal no 21/477) was exempt from the Medical Research Involving Humans Act (Dutch abbreviation: WMO). The non-WMO Committee division 3 of the Leiden University Medical Center also determined that this study (reference number 22–3003) was exempt from the WMO and therefore exempt from review by the Research Ethics Committee.

Recruitment

We recruited three groups of participants: potential users of the AI-driven cVNI (focus group 1), (former) users of a retinal implant (interview-1, −2, and −3) and current CI users who were potential users of the AI- driven CI (focus group 2). Demographic data on all respondents can be found in Table 1.

Potential users of the AI-driven cVNI (focus group 1) were approached via a call on the website of a patient organization for blind and partially sighted persons, persons with an eye condition or deafblindness. Respondents were included when identified as potential AI-driven cVNI users based on the preliminary inclusion criteria of the VNI's initial clinical trials (Supplementary Material). Recruitment was stopped when enough respondents (>4) could be included to organize a focus group. Of the five included respondents, one respondent was able to successfully submit a written signed consent form. The other four respondents gave their oral consent at the start of the focus group, which was recorded and transcribed verbatim.

Table 1. Demographics of respondents.

Demographic	Focus group 1 (potential AI-driven cVNI users)	Focus group 2 (potential AI-driven CI users/CI users)	Individual interviews ([former] retinal implant users)
Male	*n* = 3	*N* = 3	*N* = 2
Female	*n* = 2	*N* = 0	*N* = 1
Age average (range)	61 years [51-66]	55 years [41-75]	61 years [43-71]

Abbreviations: AI = artificial intelligence, CI = cochlear implant, RI = retinal implant, cVNI = cortical visual neural implant.

Retinal implant users (interview-1, −2, and −3) were contacted by a member of the INTENSE consortium (HS) who had been involved in their rehabilitation after retinal implantation and were asked to participate. After expression of interest, contacts details were shared with the research team who contacted the (former) users by telephone. All three respondents agreed to participate and provided oral consent to participate at the start of the interviews, which was recorded and transcribed verbatim. At time of the interview, one out of three retinal implant recipients was still using the device. We refer to all three respondents as "retinal implant users" throughout this manuscript.

Potential users of the AI-driven CI (focus group 2) were included via the Ear, Nose and Throat (Otolaryngology) department of the Leiden University Medical Centre. In practice, the development of an AI-driven CI comprises the development of a new AI-based software that is compatible with current CI hardware. Therefore, all current CI users could be considered potential users of the AI-driven CIs. Respondents were approached in the consultation room or via phone and email by a clinical physicist (JB) and head of research support (BM), respectively. Those who expressed interest to participate in the focus group study, received further information from BM. Those agreeing to participate then signed consent forms and provided contact details to the research team at the University Medical Center Utrecht. Recruitment was halted when enough respondents could be included to organize a focus group. Six respondents were initially included, yet two respondents cancelled last minute because of illness and one respondent cancelled because of a conflict in schedule.

Data collection

Two focus groups including in total eight respondents, and three individual interviews were conducted between December 2021 and February 2023 (Table 2). Semi-structured topic lists were used to allow users to discuss and emphasize topics that were of perceived relevance while also ensuring that important topics were discussed in all focus groups and individual interviews. Topic lists were developed based on expert knowledge of the research team. Topics included impressions and expectations of the technologies and their AI-components, and clinical trial participation (Table 3). Participants also received oral information on the technologies during the focus groups. In the CI focus group this information was also supported by images on PowerPoint slides. Full topic lists and information texts and images can be found in the Supplementary Material. Focus groups were led by OCVS, who is trained in qualitative research methods. KRJ, trained and experienced in qualitative research observed and took field notes. Focus groups were conducted via MS-Teams in Dutch. Interviews were conducted by OCVS, who also took field notes. Interviews were conducted at a location of choice of the respondents, which for all three respondents was at their homes. At interview-1 the respondent's partner was present at time of the interview. Focus groups and interviews were recorded, transcribed verbatim and pseudonymized. In this paper we report on the results from the questions on impressions and expectations of the technologies and their AI-components (Table 3).

Table 2. Focus groups and interviews.

	Topic	Participants	Duration
FG1	AI-driven cortical visual neural implant	Potential users ($n = 5$)	103 min
FG2	AI-driven cochlear implant	Potential users, current users cochlear implant, ($n = 3$)	80 min
II-1	AI-driven cortical visual neural implant	(former) user retinal implant	70 min
II-2	AI-driven cortical visual neural implant	(former) user retinal implant	64 min
II-3	AI-driven cortical visual neural implant	(former) user retinal implant	61 min

Abbreviations: AI = artificial intelligence; FG= focus group; II= individual interview.

Table 3. Sample interview and focus group questions.

Topic	Sample interview/focus group questions
Impressions and Expectations on technology	Have you read or heard anything about the neural implant being developed? If so, what is your impression of it?
	What do you expect that the neural implant would enable you to do?
Opinion on AI	We have just told you that this implant will (possibly) have an AI-component. How do you feel about that?
	What are important considerations or conditions to add such an AI component?

Abbreviations: AI = artificial intelligence.

Data analysis

Data was analyzed thematically [31]. OCVS generated initial codes based on the topic list, familiarization with the data and discussion in the research team, and coded transcripts using Nvivo12 software. KRJ critically reviewed a sample of coded transcripts, which was then systematically reviewed for supporting or conflicting evidence concerning emerging themes and codes. Final thematic coding was generated from consensus between OCVS and KRJ. We selected representative quotes to illustrate key themes and translated them into English (Tables 4 and 5). We reached "meaning saturation" when formulated themes were sufficiently understood by the team [32]. As this was an exploratory study with a small sample size thematic saturation was not explicitly aimed at.

Results

Respondents discussed several ethically relevant considerations regarding AI-driven neural implants for vision and hearing, which we clustered around two main themes: 1) Experiences and expectations and 2) perceived risks and anticipated disadvantages.

Expectations and experiences

In discussions on hopes and expectations of the AI-driven neural implants for vision and hearing, respondents discussed their improvement compared to the status quo, the expected enhancement in autonomy of users, and design requirement. Illustrative quotes can be found in Table 4.

Improvement from the status quo

Respondents generally reacted positively towards the new technologies. All groups stated that any improvement from the status quo would be welcomed.

As there is currently a lack of treatment options for *retinitis pigmentosa*, and many other conditions leading to blindness, potential users of the AI-driven cVNI considered this technology to provide an important opportunity for rehabilitation. Additionally, a retinal implant user emphasized that any small improvement in visual function could have a great impact on users (Q1, RI_1). Moreover, the increased number of electrodes compared to prior visual implant technologies like the retinal implant was expected to enable more detailed phosphene vision. To note was also that both potential users and retinal implant users expressed a general sense of trust in science and the research enterprise, and specific trust in the field of neurotechnology because of recent significant advances (e.g., the development of deep brain stimulation treatment for epilepsy) (Q2, cVNI_3). The use of AI technology in cVNIs was predominantly well-received by respondents. Retinal implant users showed a range of attitudes from extremely positive to some initial discomfort, but not distrust. Potential users of the AI-driven cVNI expressed a predominantly pragmatic attitude, welcoming AI if it could enhance image understanding (Q3, cVNI_4).

CI users expressed excitement for the development of the improved AI-based software, as they expected that it could only result in an improvement of current CIs (Q4, cVNI_3). The automation of processes through AI-based algorithmic predictions was considered a significant advantage as it could adapt settings based on context and make these systems easier to use. For instance, CI users expected that automation in recognizing contexts would reduce the need to adjust settings manually through physical buttons on the CI, or a smartphone application, which in their current systems meant that they were sometimes lagging behind in changing situations (Q5, CI_1). Additionally, if this novel AI-driven CI would allow the automatic following of a moving sound source (e.g., when in conversation at a cocktail party), this was considered a significant improvement over their current use of a directional microphone (Q6, CI_2).

Enhancement of autonomy

Many of the AI-driven cVNI and AI-driven CI respondents expected that these devices could increase users' autonomy. This was phrased in several ways.

Table 4. Illustrative quotes experiences and expectations.

#	Respondent id*	Quote
Q1	RI_1	"I also know the difference between, let's say, seeing 4% and nothing. That is a 100% difference, or even a 1000% in my opinion. You are so impaired if you can't see, and you can still do a lot with 3 or 4%".
Q2	cVNI_3	"There has already been developed so much that can restore or improve brain functions. There are people who get an implant to greatly reduce epileptic attacks. This is not the first thing that we could use in the brain".
Q3	cVNI_4	"If that AI can help with understanding those images, I think it's fantastic".
Q4	cVNI_3	"I think it could only be of added value, compared to what there is now".
Q5	CI_1	"It could be reduced, the app usage. You often get behind a bit. You switch and then there is already another situation. So at some point you keep on having to operate that app".
Q6	CI_2	"That the CI will follow the sound of you conversation partner who is moving around you, that would be a great function. I currently have a directional microphone, but I need to follow someone with my head to be able to keep on hearing them in a busy environment".
Q7	CI_1	"That is one of the things to keep in mind. When your hearing is very much impaired, that you will need to avoid certain situations. […] you can lose all your social contacts".
Q8	RI_1	"in the metro, a bit of navigation would be very pleasant. Because you […] have to go to your job, in the metro, which is always really busy. And it's just a matter of time before the crowds run you over. […] That is awful. Because you are walking and then people are running towards you on their way to a different platform. The station is big here. And then you feel all those people approaching you, while you are walking on the tactile paving through the middle of it all. […] It actually is really terrifying. […] It is terrifying when you are […] walking in a station, they are sometimes underground stations. They once hired me to participate in a test there when they had placed new tactile paving. So, I was walking there and trains kept on arriving, and because it is underground, the sounds were reflected. So you lose your hearing completely, and then you feel paralyzed because you cannot go on, you dare not go on. You just think to yourself, I'll stand here. Because you lose every part of your navigation".
Q9	cVNI_3	"It gives me a feeling of safety when I go outside because I don't see anything. People walk past you and not everybody says hi. But, if I could see who is approaching, using facial recognition, that would mean a lot to me. […] Also because I really like to talk to people.
Q10	RI_1	"If I would be in my 20s or 30s […] the device would open a new world for me, because it will definitely make you feel more confident, and perhaps you will also start feeling better in your own skin. It would definitely make me more confident because it would navigate for me, which is what I would want from the device".
Q11	cVNI_3	"I don't mind if it is visible as long as it has normal proportions […] so that you are at least able to make the movements that you currently make. So that you are not required to only walk with a completely straight back, but that you can also bend over, or get something from your bag without anything happening to the device's connection. I would like it if you were able to do what you can do now".
Q12	RI_1	"Well, I would consider it a great progress if you […] do not have to stand there like an idiot, scanning with your head. […] All that scanning will give you a strained neck and head. It drives you insane".
Q13	cVNI_4	"Well, twenty years ago there were these night vision glasses […] That was a pair of glasses […] with a thick cable and a battery. And I think: I don't see myself getting on the bus looking like a sort of moon rider with a type of ski goggles, a thick cable and a battery attached to my belt. I think it's important that it is light and compact. […] Like the Orcam where you can magnetically attach a small device to your glasses, I can see myself getting on the bus with that, so to say. It should be pretty discrete".
Q14	cVNI_5	"It should also be somewhat presentable. You are already so visible in the street, and if you then also start looking like a robot, I don't like that".
Q15	cVNI_1	"There is already that hurdle to overcome to start walking with a stick, never mind that you then also have to wear a pair of big fat glasses".
Q16	RI_2	"Not only the media, but also in the street. People approach you and ask: What is that? You are wearing something funny on your head, so people will ask questions".

* RI=(former) retinal implant user; cVNI = potential AI-driven cVNI user; CI = CI user (potential AI-driven CI user).
Abbreviations: AI = artificial intelligence; CI = cochlear implants; cVNI = cortical visual neural implant; RI = retinal implant.

CI users particularly welcomed any improvements in differentiating between and following voices. Such improvements would help them in situations that they currently considered challenging and lead them to avoid visiting certain areas, including the work floor, office parties, church, busy restaurants, and children's playgrounds. They anticipated it would further open up the possibility to engage in social interactions and reduce social isolation and thereby positively impact their autonomy (Q7, CI_1).

For the AI-driven cVNI, its benefit for users' autonomy was predominantly described in terms of functional independence. Both potential users and retinal implant users expected the device could improve independent navigation in public spaces and public transport (e.g., by identifying obstacles and reading text), also improving feelings of safety in these settings, especially for settings that were considered very scary to experience without sight (Q8, RI_1). If the AI-driven cVNI would also allow users to recognize

faces of others, one potential user describe that this would be important to them, as this could also contribute to a sense of safety in public spaces and would be helpful in initiating conversation (Q9, cVNI_3). In line with these expectations, retinal implant users also expected that the use of the AI-driven cVNI and the improvements in functional independence could boost users' confidence and give them a sense of empowerment (Q10, RI_1).

Design requirements

In addressing expectations of cVNIs, respondents also reflected on (hardware) design of the AI-driven cVNIs. Both potential AI-driven cVNI users and retinal implant users emphasized the importance of the device having a high level of usability. They valued a high level of usability of the device firstly in the sense that it should be wearable (robust, lightweight, compact, long battery duration) so that the hardware would not interfere with daily activities (Q11, cVNI_3). Reflecting on their own system, retinal implant users (had) experienced the wires in their system as a nuisance, arguing for a comfortable, flexible, and wireless design of the AI-driven cVNI, that would sufficiently and safely allow for movement. They also discussed that it would be an important advantage if the AI-driven cVNI would require less scanning (i.e., moving of the head to gain an understanding of the full image) than the retinal implant, as this was time-consuming and straining for the neck and head (Q12, RI_1).

Additionally, the aesthetics of the AI-driven cVNI was an important topic of discussion both with potential users and retinal implant users. Potential users argued for a design that would be presentable and discrete (Q13, cVNI_4), as respondents described already feeling very visible in public spaces (Q14, cVNI_5) and experiencing the use of visible aids as something to be overcome (Q15, cVNI_1). Similarly, retinal implant users described experiences of being very visible in the street using their device (Q16, RI_2), though it should be noted that not all respondents considered this to be undesirable, as one respondent enjoyed this particular experience.

Lastly, potential users acknowledged that in the design of AI-driven cVNIs trade-offs would likely need to be made, for instance between a lightweight device and battery duration. They also argued that personalization of the hardware would be important because of interpersonal differences in preferences and needs in different contexts. For instance, for the users that still have some light perception, they may need to combine the AI-driven cVNI with a hat when outside because of photophobia.

As the development of the AI-driven CI does not involve the development of new hardware, CI users did not discuss design requirements in the same way. It is however worth noting that CI users all described different contexts in which they expected to use and benefit from the AI-driven CI, suggesting that personalization of these systems for preferences and needs of individuals could be important.

Perceived risks and anticipated disadvantages

Perceived risks and anticipated disadvantages of AI-driven neural implants for vision and hearing were shared regarding uncertainty of effectiveness, operational risks related to the AI component and the device itself, surgical risks involved in cortical implantation, and media attention. Illustrative quotes can be found in Table 5.

Uncertainty of effectiveness

Though potential users shared predominantly positive perspectives on the new AI-driven cVNI, they considered the current technology to be immature and required more information to form a definitive opinion and determine their interest in being potential users. They argued that more information is needed regarding the current state of knowledge derived from preclinical and clinical development, and expected effectiveness and risks (Q17, cVNI_2).

Where CI users felt that the AI-driven CI could only offer improvements over the current technology, they did express some hesitancy regarding the novelty of the new AI-driven CI software, as they worried

Table 5. Illustrative quotes perceived risks and anticipated disadvantages.

#	Respondent id*	Quote
Q17	cVNI_2	"You just want more information. Because this is all still early on in my experience. […] So, there should be a lot more information before we can ever make a decision".
Q18	CI_2	"I do notice with hearing aids that the automatic modes, that you often want to override them because it doesn't do exactly what you want. […] Yes, in that respect I am skeptical. Would that then go well when it's in a CI?"
Q19	cVNI_2	"Don't you all have the feeling that if it is all adjusted automatically, that it is also more vulnerable? […] I also walk with a guide dog that sometimes also thinks that she knows where I want to go [but does not]. You don't want that with a computer either, that things are filled in for you. That is something I find difficult with AI. How far does it go?"
Q20	CI_3	"What is important to hear on a specific moment? […] Right now that does not go automatically. You have a filter. Like, this is important to me. So, this thing will also need to know what is important. When is that traffic important? It is when you are crossing the street, not when you are sitting on the terrace on the side of a street. How will you teach the device that?"
Q21	cVNI_5	"Nowadays you keep on hearing about hackers that break into computer systems. Can hackers break in into these things? Can they show you images that aren't there to mislead you? How safe is it?"
Q22	CI_3	"[The device] learns. So the data needs to be saved somewhere, as this will not be in the processor itself. I don't see a big risk there, not bigger than we already have with the data on our phone, password managers and location tracking. If I take off my CI somewhere, I can find it on my phone. Really, I would be able to have myself followed if I wanted to. So, what is the difference?"
Q23	cVNI_5	"Well, for example. […] There is Bluetooth [on your CI], that is a signal, but your Wi-Fi is on the same wave length. So, my Wi-Fi transmitter at home interferes with my hearing aid if I am not careful. The microwave, if I turn it on, my hearing aid shuts off, it is pushed out. And if I turn on the induction hub, I hear a huge hum in my hearing aids".
Q24	cVNI_4	"I think that the implantation in the brain is a really scary thing".
Q25	cVNI_5	"So, I feel a bit: I should support science, really I should participate in it. But I also think the risks are quite something. Especially if you hear, as I did the other day, about the area in the brain that is responsible for vision, that when you go blind, that part of the brain that is responsible for vision, as it were, takes over other tasks. For example, it starts processing touch or other impressions. For instance, that braille uses the visual part of the brain, even though you do braille by touch. And I wonder, if you have this procedure as a part of a trial, and imagine the risk that the brain area gets damaged by the implant, will I lose my sense of touch? Can I no longer read braille? Just to name something crazy. There are considerations that I worry about. What will happen to me? I find that very difficult".
Q26	CI_2	"Well, if they read-out brain waves and things like that, I do get a bit wary. […] I wonder how that is going to be realized. Will there be electrodes in your brain? I found it scary to get a CI, there is drilling into the cochlea, which gets damaged by the wire that they put in there. But if they also get into your brain, I don't necessarily want that".
Q27	RI_3	"Maybe it is cold feet, but I really do have a type of trauma from that, really. […] And I was so proud that I was so psychologically stable… Well, it would make you instable. I thought it was horrible".
Q28	RI_3	"Well, you don't know where they get it from! All the reporting that wasn't true at all: "Blind grand[parent] can see [their] grandchildren again after so many years!" […] Well I never said such thing because I never experienced it like that. I would never, so I was quoted on things I had never seen in my life".
Q29	RI_2	"So they write it down that way, because those news papers want to score, and that really affected me. Because I now felt like: oh well, now I also have to perform, you know. Now I have to be better than [that other user] and the rest of the world. That bothered me. I really needed to temper that [feeling]".
Q30	RI_3	"… I hadn't sufficiently realized that you don't only have to deal with your own expectations, but with those of a lot of people. Of your family, your kids, your grandchildren, people who are also very excited at the [hospital] and the [rehabilitation institution]: everyone who participates in [the project] that is full of expectations".
Q31	RI_1	"I should have been able to see twenty times already, with all the promises of science and stories in the media on what they are working on. I think I have thought about four or five times that I might be able to see again in a few years. Because people didn't hold their… The expectations never came true".
Q32	RI_3	"I am not sure […], before you start [the trial] this should be discussed very well, maybe you need a type of training for that. I am not sure if people are screened on it, because it is really intrusive".

*RI =(former) retinal implant user; cVNI = potential AI-driven cVNI user; CI = CI user (potential AI-driven CI user).
Abbreviations: AI = artificial intelligence; CI = cochlear implants; cVNI = cortical visual neural implant; RI = retinal implant.

that this software may already exist in certain hearing aids. Additionally, as limitations continue to exist in the software of these existing hearing aids (i.e., mistakes in prediction on desired sound stream), one respondent reported being skeptical that these problems could be solved in the AI-driven CI (Q18, CI_2).

Operational risks

Having identified automation as an important advantage of AI-driven systems, potentials users of the AI-driven cVNI and AI-driven CI equally identified the risk of mistakes in algorithmic predictions as an

important downside of this level of automation in these devices. Wrongful predictions, for instance, were considered to increase a user's vulnerability (Q19, cVNI_2). Respondents therefore reported the need for a balance between the benefit of automation and remaining in control. A requirement for sufficient levels of user-control was also named by CI users, who expressed the need to be able to correct for mistakes in predictions, and the possibility to provide feedback to ultimately also "teach" the system, so that predictions will better match the user's preferences (Q20, CI_3).

Some respondents worried that the AI-driven device may have the risk of being hackable. Potential AI-driven cVNI users for instance worried about the possibility of hacker-generated misleading images entering the system (Q21, cVNI_5). Drawing a comparison with existing consumer products, CI users however considered such privacy risks to be very low, at least lower than for smartphones, which are used daily (Q22, CI_3).

A final operational risk for the AI-driven cVNI was shared by a potential AI-driven cVNI user who, living with Usher's disease, was also a user of a CI. They expressed a concern on whether other appliances in the user's environment could interfere with the AI-driven cVNI's performance, as their CI system could to be interfered with by for instance Wi-Fi signals, microwaves, and induction stoves (Q23, cVNI_5). Other potential AI-driven cVNI users agreed that this would be an important risk to consider.

Surgical risks

Most respondents expressed concerns regarding perceived safety risks involved in cortical implantation of the cVNIs. For some potential AI-driven cVNI users the cortical implantation of the device was considered frightening (Q24, cVNI_4). Respondents also reported concerns regarding potential secondary risks of cortical implantation, such as long-term headaches, losing any residual vision, and impact on other sensory function and skills like braille reading that were currently factors essential to their daily functioning (Q25, cVNI_5). One retinal implant user expressed hesitancy towards cortical implantation which they expected to involve more severe risks than retinal implantation.

For CI user, concerns regarding surgical risk were, as expected, only mentioned in case a future prototype of the AI-driven CI would include cortical implantation of a component for hearing intention decoding. Some considered this option to be even more frightening and risky than the implantation of the CI in the cochlea they had experienced, and considered this a potential reason not to opt for such a cortical implant (Q26, CI_2).

Media attention

Lastly, retinal implant users shared that they had experienced high levels of media coverage in the post-implantation phase. All respondents had experienced the level of media attention as intrusive to their own lives. One respondent recollected several interactions with the media which had been highly intrusive, distressing, and traumatic (Q27, RI_3). In contrast, another respondent described enjoying the attention of the media, though also admitting that journalists in search of a "scoop" can be bothersome. In addition, retinal implant users also described how there was a strong discrepancy between the portrayal of the device's effectiveness in certain media and the (much lower) level of effectiveness they experienced (Q28, RI_3). Such reporting created a sense of unease, but also feelings of pressure to perform, or even to compete with other users (Q29, RI_2). Moreover, this reporting was perceived to raise expectations regarding the effectiveness of the device, and respondents described struggling in dealing with expectations of others, including loved ones and the medical team involved (Q30, RI_3). In addition, a respondent also warned that such unfulfilled promises can lead to frustration in patients, especially as promises for the treatment of blindness have been widespread over the years (Q31, RI_1). Retinal implant users therefore argued that media should stick to a realistic and factual portrayal of such technologies. In addition, they argued that users of the AI-driven cVNI are vulnerable and should receive support and training to deal with such media coverage (Q32, RI_3).

Discussion

Our study explored perspectives of former, current, and potential users of (AI-driven) neural implants for vision and hearing and aimed to identify ethically relevant considerations. Reflecting on expectations and experiences, we found that respondents generally held a positive view of these emerging technologies and expected these devices to improve users' autonomy, predominantly in terms of functional independence for AI-driven cVNI users, and in accessibility of certain noisy environments for AI-driven CI users, also reducing social isolation. Respondents expressed pragmatic attitudes towards the use of AI in these devices, welcoming it if it could improve the functioning of the devices, yet recognized a potential tension with reduced levels of user control. Potential AI-driven cVNI users also shared considerations regarding aspects of these devices that did not relate to their use of AI-technology specifically and may be more broadly applicable to (visual) neural implants. Regarding perceived risks and anticipated disadvantages, we found that cortical implantation of a device raised feelings of fear and potential users require more information of the exact risks to be involved. Moreover, reflecting on design of the AI-driven cVNI, respondents notably emphasized the importance of usability as well as discretion and aesthetics in hardware design. Lastly, retinal implant users reported that media attention covering neural implant users could be an undesirable consequence for users of (AI-driven) neural implants. In the following sections, we will interpret our findings in the light of existing (empirical) literature, and will highlight previously underrepresented or underexplored issues.

Empirical studies of (potential) visual neural implant user perspectives

While the application of AI in neurotechnologies is on the rise [1,2,33,34], to our knowledge empirical studies on perspectives of potential users of AI-driven neural implants for vision and hearing have not been reported. Empirical studies including former, current or potential users of VNIs more broadly are also scarce, though a small number of studies have been published regarding potential users' perspectives on trial participation for a cortical neural implant [19,35,36], a retinal implant [37] and an optical nerve implant [38], and regarding trial participants' experiences of the cortical Dobelle implant [9,39]. This current work aims to contribute to this limited body of literature by addressing perspectives on the development and use of an AI-driven cVNI.

Though perspectives on trial participation are outside of the scope this current work, our study echoes the finding that increased safety and independence is described as an important aim by potential (AI-driven) cVNI users [40], and that potential users of (AI-driven) cVNIs share uncertainty on expected effectiveness and possible types of risks [19].

More recently, Karadima et al. [41] conducted an empirical study exploring the attitudes of potential recipients toward emerging visual prosthesis technologies (including thalamic, retinal and cortical implants) more broadly, of which the first quantitative data have been published [41]. Karadima et al. [41] report that for potential users the perceived risks still outweighed perceived benefits of all three types of visual prosthesis technologies, with the most negative overall impressions of the cortical implant [41]. They concluded that negative impressions were predominantly due to technological limitations of current devices and that "substantial advances are still required before broad acceptance of visual prostheses will be found" ([41], p.12). Though respondents in our study overall shared more positive impressions the AI-driven cVNI, they similarly considered the technology currently too immature to provide a definitive answer. However, the comparison of results between these studies is limited by their quantitative and qualitative methodology.

Empirical studies of CI user perspectives

In contrast to the limited body of empirical literature on patient perspectives on VNIs, empirical studies regarding (potential) user perspectives on existing CIs have been widely reported over the past decades. Studies include perspectives on decision-making on CI implantation in adults [42], expectations and experiences of CI use in adults [27,28] and in young CI users [43,44], and parental perspectives on CI implantation in children [23–25,45–47]. While some studies do describe acoustical shortcomings of

existing CIs and a desire for improved speech comprehension in noise [17,27,43,44,48], to our knowledge there a no studies addressing CI users' perspectives on the development and use of (AI-based) software for the improvement of speech-perception in noise. Still, similar to our study in which a reduction of social isolation was described as an important expectation of the improved AI-CI, a reduction of social isolation was also described as a primary motivator for the adoption of current CIs [26], and as one of the primary experienced benefits [27]. Therefore, further improvements for speech-in-noise in AI-driven CIs may continue to better address this important need.

Artificial intelligence in AI-driven neural implants for vision and hearing

Addressing the use of AI technology in AI-driven neural implants for vision and hearing, our study showed that AI did not substantially reshape (potential) users' fears or concerns on these technologies. The most prominent ethical concern related to the use of AI in this study related to potential errors in algorithmic predictions. While the use of predictive functions in AI-driven neural implants for vision and hearing aims to improve automation and efficiency of signal processing, and in turn improve the performance of devices, mistakes in algorithmic prediction may not only result in feelings of vulnerability and reduced trust in the device, but can also impact users' control over the device. As respondents suggested that design of these devices should allow users to exercise sufficient levels of user-control over the device (e.g., through correcting and "teaching" the device their preferences), developers may be required to reflect on the trade-off between user control and automation, on what would constitute sufficient control, and how to account for individual preferences [49]. Similar questions are also discussed in ethics literature on other neurotechnologies using predictive algorithms, such as brain-computer interfaces for speech, which may provide valuable input for addressing these questions in AI-driven neural implants for vision and hearing [49].

In the scholarly ethics literature on the convergence of AI and neurotechnology, there is widespread concern and attention for neurotechnologies' potential hacking and brain-reading abilities [50]. These concerns have for instance also contributed to the call for the development of new neurorights to protect users of neurotechnologies [51]. Notably in our study, these concerns were sparingly addressed by respondents. Some potential cVNI users in our study indeed shared some concern about risks for hacking of the device, as they were familiar with hacking risks of computers in general. Interestingly CI users used the comparison with poor user-privacy in consumer products (i.e., smartphones) to temper privacy concerns for AI-driven CIs, putting them in perspective with existing limitations to the privacy that are (arguably) commonly accepted. Additional empirical studies with prospective users of AI-driven neurotechnologies would be valuable for assessing if ethicists' concerns on hacking and brain-and mind-reading abilities of these technologies are shared by this population. Of note here is that concerns on brain- and mind-reading abilities may be more prominent among (potential) users of (brain) decoding rather than stimulating devices. Still, the reasons and causes for the limited influence of the use of AI in these technologies on respondents' concerns and fears remains unclear and warrants further investigation. We speculate this may be caused by a primary focus on other types of concerns, difficulties imagining the contributions and effects of AI-layers in these devices, or simply a positive impression of AI and little concerns.

Surgical implantation

Our study suggested that the required procedure of cortical implantation could be a potential barrier for uptake of future cVNIs. In addition to feelings of fear related to the procedure itself, respondents were also worried whether other remaining senses and skills would be impacted, as these are essential to their functioning in daily life. Considering that it is uncertain how long the cVNI will remain functional, risks affecting other senses and for instance braille reading skills can have severe long-term impacts on user's independence and quality of life. To note is that concerns on surgical implantation are not limited to AI-driven (visual) neural implants specifically. As such, concerns on cortical implantation of cVNIs are echoed by the study of Karadima et al. [41] who report that surgical risk significantly influenced subjects'

preferred approach (i.e., retinal, thalamic or cortical). Only 4% of 28 respondents preferred the high-risk cortical implant over retinal and thalamic options, considering factors like surgery, visual perception, and therapeutic benefits [41].

Visibility of neural implants for vision and hearing

Another aspect of cVNIs of concern to respondents that may influence the uptake and use of cVNIs is the visibility of the technology. Our study suggests that a highly visible device could cause some users to feel uncomfortable in public spaces, which could restrict their mobility. Such impacts are of concern as they run counter to the aim of these technologies to increase autonomy of individuals living with blindness. Though concerns on visibility of neural implants are not likely to be unique to AI-driven cVNIs specifically, to date, the aesthetics of (visual) neural implants is a topic that is hardly covered by academic literature. The limited attention to this topic may stem from the experimental development stage of most neural implants, the potential perception of developers and ethicists that aesthetics is considered less important compared to technology benefits and risks, or, specifically for VNIs, a possible assumption that aesthetics is not important for the visually impaired user population. An exception can be found in the literature on CIs and (non-implanted) hearing aids, where aesthetic or cosmetic aspects are discussed in the context of technology uptake [42,52–54]. For hearing aids, issues relating to aesthetics and cosmetics pose a well-documented barrier to adoption, which is attributed to factors such as the stigma associated with hearing loss, individuals' self-perception, ageism, and vanity [54,55]. For CIs it has so far been found that though cosmetics of devices are a concern, the functionality of the devices remains a priority for users [42,53,54,56]. Yet, research concerning aesthetic and cosmetic considerations on CIs and how these relate to perceived stigma and quality of life are scarce [54]. Rapport et al. [54] therefore argue that "given the widespread underutilization of CIs, an exploration of the relative importance of cosmetic concerns with respect to these new technologies is warranted"(p.3). In a similar way we would suggest that further in-depth research into perspectives of potential users on the aesthetics of (AI-driven) (cortical) VNIs would be valuable to explore how aesthetics could influence the use of these VNIs and the perceived sense of autonomy in users. These perspectives could help identify potential barriers for uptake in early stages of development and can prevent incorrect assumptions in this area.

Media coverage of emerging neurotechnologies

Last, another potential negative impact on the autonomy of neural implant users more broadly could be the media-coverage of emerging neurotechnologies, as reported by retinal implant users, who experienced this as very intrusive, impacting their privacy and daily lives. Such experiences may negatively impact the newly regained sense of autonomy. Current studies on media coverage of neurotechnology predominantly seem to discuss the topic of neurohype (i.e., news and entertainment media oversimplifying and sensationalizing neuroscientific claims [57]), yet overlook the potential impact of such neurohype on trial participants and initial users. With the expected rise of various neurotechnologies entering clinical trials in the coming decades, along with increased media coverage and public enthusiasm for neurotechnologies and AI, it is essential to develop strategies for user protection, including the responsible and ethical communication of neuroscience findings [58].

Methodological reflections on focus groups with participants

In organizing this study, we experienced valuable assistance from the relevant patient organizations. For the focus group with potential users of the AI-driven cVNI, any initial challenges for participants to partake in an online meeting (mandated by COVID restrictions) were significantly reduced by the assistance of a patient organization representative who, prior to the meeting, made sure all participants were able and comfortable in joining the MS teams meeting online. During this virtual meeting with the potential users of the AI-driven cVNI, we observed an impressive level of problem-solving and self-organization

among the participants, as participants quickly found a way to facilitate natural discussions in absence of visual cues. They established a simple convention where, before replying or making a comment, each respondent would introduce themselves by name. This worked well and allowed for a fluent and lively discussion.

For focus groups with CI users, we received valuable advice from the patient organization, suggesting the use of a live captioning service to provide real-time subtitles during the session. Respondents responded very positively to this support, as it alleviated their initial concerns about the online format. This demonstrates that while engaging in (online) patient participatory research with potential VNI and CI users comes with some challenges, it is possible when tailored to the specific needs of the users.

Strengths

To our knowledge, out study is the first empirical study covering perspectives of potential users on AI-driven neural implants for vision and hearing, also identifying perspectives on design aspect of these devices. By also including (former) users of a retinal implant, we were able to include perspectives on AI-driven neural implants grounded in existing experiences with a similar technology. Our qualitative approach enabled us to identify distinct, in-depth and firsthand insights from potential, current and former users of neurotechnologies, which would not have been captured through quantitative methods like standardized surveys.

Where our study provides unique perspectives on AI-driven neural implants for vision and hearing, several findings in our study relate to aspects of these technologies that do not pertain to their AI-component. These finding may be more broadly applied to neural implants for vision and hearing that do not use AI technology, other types of neural implants, and neurotechnologies in general. Our study therefore also provides a valuable contribution to the broader empirical ethical literature on patient perspectives in the context of neurotechnologies.

The EPR approach applied in this study involved "ethics from within" meaning that we, as ethicists, were embedded in the structure of a multidisciplinary consortium in which the AI-driven VNI and AI-driven CI are under development, closely collaborating with developers and experts (e.g., an active role in steering committee; regular formal and informal knowledge-exchange, including presenting early-stage research to research groups for feedback and insights from other disciplines; joint writing; and co-hosting regular multidisciplinary meetings) [29]. This approach offered several benefits, including our being informed on the latest technological advancements and possibilities and recruitment of respondents based on realistic eligibility criteria.

Limitations and future perspectives

Our study also had limitations. To start, the EPR approach also had some disadvantages, including the preselection of our use-cases, which has restricted our inclusion of other potentially relevant use-cases. Next, this study includes perspectives of (former) users of a retinal implant and perspectives of prospective users for an AI-driven cVNI and AI-driven CI. The AI-driven cVNI and AI-driven CI are technologies still under development, meaning that impressions of the technology and expectations about these technologies were oftentimes intertwined, making it impossible to analytically distinguish between impressions and anticipatory expectations. Relatedly, a limitation of this study is the uncertainty regarding respondents' actual knowledge of AI, coupled with the fact that the technology is still in its early stages of development, making it unclear whether their expressed fears and hopes are based on informed understanding or speculative impressions. Additionally, we identified challenges in the recruitment process for this study, which contributed to the small size of the study population, and our choice for an exploratory thematic analysis. As such, considering the overall low number of participants in this study, this study should be considered exploratory. It is likely that additional studies with CI-users, potential AI-driven cVNI users and retinal implant users will identify additional ethically relevant considerations. Reflecting on the recruitment challenges, we speculate that the online format of the focus group with CI users may have discouraged potential participants to participate, as respondents in our

study shared having had concerns about this format prior to the focus group because of poor experiences with online group meetings as CI users. Due to last-minute cancellations of participants in our focus group with CI users, only three participants were included, which is a relatively low number for conducting focus groups [30]. Our study only included current adult CI users and not individuals who opted against current CIs systems, for any reason, such as objections from the Deaf community or known limitations of current devices. Including these individuals could provide valuable additional insights on the use of AI in CIs. Moreover, as young children with CIs may also become users of the AI-driven CI, children using CIs or their parents could also be included in further studies. Reflecting on difficulties in recruitment with potential AI-driven cVNI users, we speculate that this may relate to our use of the preliminary inclusion criteria for the anticipated AI-driven cVNI's first-in-human trial. We chose to adhere to these inclusion criteria to prevent raising undue expectations on eligibility for the AI-driven cVNI first-in-human trials. Considering the progressive nature of some conditions leading to blindness, it could also be valuable to include the perspectives of individuals who are expected to meet these criteria in the future. To note is also that most respondents in the AI-driven cVNI focus group (3/5), and all retinal implant users (3/3), suffered from vision loss due to retinitis pigmentosa. This is only a minority of the types of patients that could be considered potential users of AI-driven cVNIs. Moreover, recruitment of respondents through a patient organization could potentially introduce a selection bias regarding predominantly active and interested patients familiar within the organization, excluding some potential AI-driven cVNI users. At the same time, collaboration with patient representatives may have also mitigate unconscious biases or assumptions of the research team, who in this study were all able-bodied individuals. Last, during our interviews and focus groups, participants were provided with information about the technologies (Supplementary Material). Despite our efforts to formulate and present the information as factually and neutrally as possible, it is important to recognize that the content and tone of this information may have influenced participants' perspectives.

Conclusion

This exploratory study suggests that potential users of AI-driven neural implants for vision and hearing expect these neural implants to, predominantly positively, affect their autonomy in terms of functional independence and mobility, which has been diminished by the conditions they live with. Our findings highlight the considerable importance that potential users attach to aesthetics of these devices, and the option to have sufficient control over the device while maintaining the benefits of the device's predictive functions. These findings underscore the value of including first-person perspectives of potential users in early stages of development and design of these technologies. Such patient involvement allows developers to remain responsive to users' needs and perspectives and develop ethically robust technologies.

Acknowledgements

We would firstly like to express our gratitude to all respondents for their participation in this study. We would like to thank Henk Stam, Jan Koopman and Dick Onnink for their interest and advocacy for patient involvement in the INTENSE consortium and the valuable conversations in early stages of study design. We also thank Henk Stam for his assistance in recruitment. We furthermore thank Petra Kortenhoeven of the Eye Association Netherlands (Oogvereniging) for her invaluable assistance in recruitment and organization of the focus group. We also thank Berber Mol and Jeroen Briaire of the Leiden University Medical Center for their assistance and coordination of recruitment at their institution. Lastly, we thank Pieter Roelfsema for his valuable feedback on the final draft of this manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the NWO under Grant number 17619.

Notes on contributors

Odile C. van Stuijvenberg is a PhD candidate at the Bioethics and Health Humanities Team at the department of Global Public Health and Bioethics department of the Julius Center, University Medical Center Utrecht. Her PhD project focuses on the ethical aspects of AI-driven neuroprostheses as a part of the INTENSE (Innovative neurotechnology for society) consortium. She has a background in pharmaceutical and regulatory sciences, and bioethics.

Katherine Bassil is a neuroscientist and assistant professor in neuroethics at the Julius Center for Health Sciences, UMC Utrecht. Katherine's research focuses on the ethical and societal challenges associated with neuroscience research and (AI-based) neurotechnologies, both within the research context and beyond. For instance, her current research projects focus on the research ethics of the explantation of brain devices in research trials, the ethics of AI-based tools in the field of psychiatry, and the ethics of predictive biomarkers for neurological and psychiatric disorders. She is the ethics lead of the Wellness working group of the international IEEE Neuroethics Framework initiative, and a longtime member of the International Neuroethics Society (INS). She is the founder of "Neuroethics Today", an educative platform aimed at raising awareness on the ethical, legal, and societal implications of neuroscience research and neurotechnology.

Marike L. D. Broekman is professor of Translational Neuro Oncology and neurosurgeon at Leiden University Medical Center and Haaglanden Medical Center. She is member of the board of the European Association for Neurosurgical Societies, president of the Scientific Board of Kika (Dutch foundation for pediattric oncology), and vice chair of the Council for Medical Sciences of the Royal Dutch Academy for Sciences. She is an editorial board member of the medical journals Acta Neurochirurgica and Brain and Spine.

Annelien L. Bredenoord is professor of ethics of technology and an international pioneer in the ethical evaluation of emerging biomedical technologies. Such as artificial intelligence, genome editing, biobanking and regenerative medicine. With her team, she has developed a unique approach to bringing (the ethics of) emerging biomedical innovations into society, called "ethics parallel research". Bredenoord served as a senator in the Dutch Senate from 2015 to 2023, including four years as faction leader. She was appointed Rector Magnificus of the Erasmus University Rotterdam in September 2021 and was recently appointed President of the Executive board.

Johan H. M. Frijns is an ENT consultant and professor of Otology and Auditory Physics, head of the Center for Audiology and Hearing Implants Leiden (CAHIL) and of the LUMC Expertise Center for Rare Ear Diseases. He is also Medical Delta professor of Electrical Stimulation of the Human Nervous System with a part-time appointment at the EEMCS faculty of TU Delft. Since 2006 he has been a Dutch member of the Collegium Otorhinolaryngologicum Amicitiae Sacrum (CORLAS)

Karin R. Jongsma is associate professor of Bioethics at the Julius Center of the University Medical Center Utrecht. She leads a research group focusing on the ethics of (bio)medical innovation, including amongst others digital medicine, neurotechnology and regenerative medicine.

ORCID

Odile C. van Stuijvenberg http://orcid.org/0000-0001-7766-6853
Katherine Bassil http://orcid.org/0000-0002-4424-9938
Marike L. D. Broekman http://orcid.org/0000-0002-0226-0119
Annelien L. Bredenoord http://orcid.org/0000-0002-7542-8963
Johan H. M. Frijns http://orcid.org/0000-0002-1180-3314
Karin R. Jongsma http://orcid.org/0000-0001-8135-6786

Data availability statement

The data supporting the findings of this study are not publicly available due to their containing information that could compromise the privacy of research participants. De-identified data are available from the corresponding author upon reasonable request.

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