Questions of Informed Consent Relating to the Use of Haptic Suits as Assistive Technologies for Persons with Development and Intellectual Disabilities*

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Cuestiones acerca del consentimiento informado relacionadas con el uso de trajes hápticos como tecnologías asistenciales para personas con discapacidad intelectual y del desarrollo

Abstract: Technological innovation is seeing the convergence of haptic technologies with real-time 3D virtual environments and/or augmented reality technologies. Amongst the diverse applications of these innovations is their use as assistive technologies (ATs) for persons with developmental and intellectual disabilities, or persons with cognitive deficits, such as dementia.

This paper focuses on the question of informed consent in relation to researching and using these technologies (hereafter referred to simply as haptic suits). Informed consent is a standard requirement in research ethics, as well as in care scenarios, so it will be required for trials of haptic suits in general, and, when used as an ATs, will be required for use in care settings. Given the emphasis on involving persons with intellectual or developmental disabilities (PIDD) in researching and designing ATs for their use, the question of informed consent is urgent.

Keywords: Assistive technologies, haptic suits, informed consent, persons with intellectual or developmental disabilities

Resumen: La innovación tecnológica está presenciando la convergencia de las tecnologías hápticas con los entornos virtuales 3D en tiempo real y/o las tecnologías de realidad aumentada. Entre las diversas aplicaciones de estas innovaciones se encuentra su uso como tecnologías asistenciales para personas con discapacidades de desarrollo e intelectuales, o personas con déficits cognitivos, como la demencia.

Este artículo se centra en la cuestión del consentimiento informado en relación con la investigación y el uso de estas tecnologías (en lo sucesivo denominados simplemente trajes hápticos). El consentimiento informado es un requisito estándar en la ética de la investigación, así como en los escenarios de atención, por lo que será necesario para los ensayos con trajes hápticos en general y, cuando se utilicen como tecnología asistencial. Dado el énfasis en la participación de las personas con discapacidad intelectual o del desarrollo en la investigación y el diseño de las tecnologías asistenciales para su uso, la cuestión del consentimiento informado es apremiante.

Palabras clave: Tecnologías asistenciales, trajes hápticos, consentimiento informado, personas con discapacidades intelectuales o del desarrollo

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1. Assistive Devices

While all technologies can be said to be intended to assist us in some fashion, the term assistive technologies is an umbrella term for technologies being designed to help certain cohorts – for example, the elderly, people with disabilities, or people with dementia. The World Health Organisation proffers the following definition:

> *"Assistive devices and technologies are those whose primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being. They can also help prevent impairments and secondary health conditions. Examples of assistive devices and technologies include wheelchairs, prostheses, hearings aids, visual aids, and specialized computer software and hardware that increase mobility, hearing, vision, or communication capacities." (WHO, n.d.)*

Markets for ATs are increasing in response to greater awareness of the plight of people with disabilities. ATs not only provide a means of aiding these individuals but can also improve the lives of carers. This is, as we will see, particularly relevant to haptic suits. Not all haptic suits will qualify as ATs, though it will be possible to adapt some extant haptic suits to use as ATs or to develop haptic suits specifically as ATs. Different jurisdictions use different definitions of assistive devices, so whether haptic suits will be considered an AT everywhere or not is unclear. However, it seems apparent that haptic

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suits will facilitate greater participation and can enhance overall well being. So, for the sake of this paper, we will consider haptic suits as ATs.

2. Haptic Technologies

Haptic technologies are designed to recreate the sense of touch by applying forces, vibrations and motions to the user. Haptic suits are suits, either full body or torso, designed to give haptic feedback to the wearer. Haptic technologies might also use sensors that will measure the forces exerted by the individual on a virtual object. They have been primarily designed for use in virtual realities, particularly for gaming. They have been more recently combined with technologies that use real-time 3D scanning with real-time virtual reality, mixed reality, and augmented reality environments - again gaming is the primary intended use, as is the case with Microsoft's Holoportation.

The technology is now being explored as a form of assistive device, as is the case with *embraceID*. This technology is intended to make it easier for aging family carers to communicate with their children with complex needs, e.g. intellectual disability, cognitive deficits, or autism. Specifically, it "aims to transmit realistic, gentle sensory data from one user to another. Numerous sensors in each haptic garment will communicate a precise sensation of weight to a specific location. This will be experienced by both parties in real time and will be synchronous with 3D visual data from emerging technologies"

Numerous benefits for both users and carers are predicted. The developers of *embraceID* outline three major benefits the technology will provide, namely the feeling of presence, actual eye-contact, and physical contact. Currently actual eye-contact, the feeling of presence, and physical contact are unavailable through our current means of long-distance communication, such as Skype, Viber, Facetime, or WhatsApp, but are of immense importance to both the carers and their children. This is of increasing significance as carers age and struggle to look after children with complex needs, with the result that the children move into new accommodation, e.g. purpose-built residences. This can be detrimental to the health of carers, who are often faced with long journeys to visit their children or with the risk of social isolation and its associated physical and psychological health implications, including an increased risk of Alzheimer's disease, declines in cognitive functioning, and less physical activity.

Utilising haptic technologies with augmented reality and virtual reality means that carers will get to interact with their loved ones in a more realistic way – eye contact will be possible (or seem possible), physical contact will be enabled through the haptic technologies resulting in a feeling of being present with the person. This can be expected to have positive psychological results as researchers have suggested that a realistic sense of presence can lead to a more intense emotional experience.

3. Informed Consent

The doctrine of informed consent has risen to prominence in recent decades. It is particularly associated with bioethics, where it has usurped an older paternalistic model that placed

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power and trust in the hands of medical professionals. Recently, informed consent has come to prominence in debates around Big Data, data mining, and novel technologies. According to Beauchamp and Childress (2009) "informed consent is an individual's *autonomous authorization* of a medical intervention or of participation in research". Informed consent "is usually understood as informed, voluntary, and competent consent (cf. Eyal 2012)".

ATs such as *embraceID* could be considered as medical/therapeutic devices or as simple communication devices. This complicates questions of informed consent once they are available for widespread use – with informed consent requirements being more stringent for medical/therapeutic treatments than for non-medical devices. Further, the intended users of ATs – PIDD – add to the confusion, as the degree of competence of PIDD is unclear. Indeed, it has been argued that we "lack a satisfactory account of informed consent for treating individuals with moderate and severe intellectual disabilities".

4. PIDD and Informed Consent and Proxy Consent

Intellectual and developmental disabilities exist on a spectrum. Some PIDD will be able to provide informed consent in the right conditions and if everything is explained sufficiently clearly. In cases where the user is capable of providing informed consent there is no particular problem regarding haptic suits – either for research or for therapeutic use. Either it is given or it is refused. Things become trickier as we move along the spectrum – some PIDD may be non-verbal, but capable of understanding the issues. In these cases, some other method of verifying whether or not they have consented will be required. This is not the case with all PIDD – some PIDD will have cognitive deficits of such severity that they will be incapable of providing informed consent. For instance, it might be impossible for them to understand what is being explained.

In discussions of informed consent, there are numerous debates about what constitutes being sufficiently informed. A person is considered insufficiently informed if they have been deceived, lied to, or have not received full disclosure, for instance. This is an issue relating to the integrity of the researchers, and in this instance, we will assume that they will be honest with their participants. The significant problem for researchers working on ATs such as *embraceID* will be the failure of participants/users to fully comprehend the information that is being presented to them. Then there will be cases where the user will not be capable of comprehending in any meaningful sense.

In cases when the person about to undergo a treatment, participate in research, or use a device is not competent to provide consent, proxy consent will be required, i.e. a parent, guardian, or someone else responsible for the person provides consent on behalf of the user. Usually, proxy consent is justified according to a right to an open future, substituted judgement, or best interests. However, for users of haptic devices, the right to an open future or substituted judgement will not apply to users who were never competent nor are ever likely to be competent. In these cases, then proxy consent must rely on the best interest standard. I will return to this topic later.

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5. Informed Consent in Research, Treatment/Therapy, and Everyday

The requirements of informed consent will vary depending on whether the technology is being used in a medical/therapeutic, research, or domestic environment. "All sound ethical thinking about clinical research, and the regulatory framework for review of protocols for clinical investigation, depends on a basic distinction between research and therapy". Whilst clinical research "is not a therapeutic activity devoted to the personal care of patients. It is designed for answering a scientific question, with the aim of producing 'generalizable knowledge'. The reason for creating such a distinction is that researchers' interests – the pursuit of knowledge – will not always align with patients' interests, whereas physicians' interests are expected (in normal circumstances) to align with patients interests in medical/therapeutic contexts.

Informed consent is required for medical treatment/therapy, except in circumstances when the person is incapable of providing informed consent, but can be expected to consent, e.g. a person in need of emergency treatment following an accident. In circumstances where a person is incapable of providing consent, e.g. they are unconscious, some treatments will be permissible. Carers will continue to change bed sheets, etc., without obtaining consent, as this is required for the patient's well-being.

The requirements of informed consent are more stringent in research contexts, as the patients are not likely to personally benefit and may be at risk for the benefit of others. Research is intended to develop or contribute to generalised knowledge. Medical/therapeutic contexts are less regulated as they are focused on the patient's best interests and rely on proven benefit and acceptable risk. In order for research to be ethically justified, it "must satisfy several conditions, including (1) a goal of valuable knowledge, (2) a reasonable prospect that the research will generate the knowledge that is sought, (3) the necessity of using human subjects, (4) a favourable balance of potential benefits over risks to the subjects, (5) fair selection of subjects, and (6) measures to protect privacy and confidentiality". Obtaining informed consent can be considered a seventh condition.

Outside of these contexts, if someone is using a device at home for personal purposes consent will not usually be required. Exceptions are when a person is required to agree to terms and conditions, e.g. when signing up to a Facebook, etc. We will now address each of these stages in terms of haptic suits.

5. Haptic Suits, Informed Consent and User Involvement in Research

Testing haptic suits at the experimental stage will have the strictest informed consent requirements. Most of the testing can take place without involving PIDD, reducing one of the complications. PIDD will not need to be involved prior to a certain threshold of effectiveness being reached, e.g. users of the suit are able to interact in the virtual environment, the tactile sensations work as they are supposed to, etc.

Once the threshold is reached, it will be necessary to determine how PIDD react to using a haptic suit. If haptic suits are to be used in care scenarios, researchers will need to know whether PIDD will interact with loved ones as if they are in physically present and whether

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any emotional benefits will accrue. The design of the Virtual Reality/Augmented Reality (VR/AR) will also benefit from the input of users with IDD and/or autism, as they might have very specific responses to the layout of the VR/AR. In cases of users with moderate or severe disability there will be difficulties – it will not be clear that they are likely to benefit at all from initial use of the haptic suit.

The fourth condition required in research - the favourable balance between risks and rewards - is the one of most concern[1]. The *immediate* risks associated with using haptic suits as assistive technologies for PIDD are likely minimal. Putting on a suit might be uncomfortable or unpleasant for some PIDD. This will have to be assessed by researchers on a case-by-case basis. Informed consent will be required before a PIDD has a suit put on them. If the PIDD is non-verbal, an alternative means of acquiring consent will be required. While the effects of immersion in a virtual reality or augmented reality will be the main focus of research interest, alongside the benefits of interacting with loved ones, researchers will need to cognisant of the impact of suddenly removing people from the VR/AR.

The sixth condition – focused on protecting privacy and confidentiality – is also of great interest. Haptic suits will be able to gather and store huge amounts of data about the person, including physiological data. In many cases PIDD will not be fully aware of the extent to which their data is being gathered or of the ways in which this data can be used. Both in trials and during use extremely strong measures to protect users of haptic suits will be required.

The benefits are uncertain in the case of PIDD as a whole but are present for their loved ones. It is plausible that being able to communicate with parents remotely will be beneficial to many PIDD. So, although participation in an experiment is not necessarily going to provide a PIDD with any benefit, the risks are minimal, while the benefits to the group as a whole are likely. These benefits are likely to be psychological and only apparent over a long time. So, while the initial experiment to determine whether the suits work (the interactions with loved ones are realistic and pleasant) will not require the participation of PIDD, determining whether the suits promote psychological well-being will require a longitudinal study.

6. Haptic Suits in Treatment/Therapy and Everyday

If it becomes apparent that haptic suits are medically or psychologically beneficial to PIDD in care, it is likely that they will be used as part of an ongoing treatment. For instance, if regular communication between users and parents/guardians is proven to have psychological benefits, this sort of communication might form part of a treatment.

However, this sort of treatment would still require informed consent. This is not true of all treatments – consider for example a person in a coma who needs bed-sheets changed. Haptic suits are not necessary in this sense. The user will have to consent to wearing the suit (and to having their data recorded, if that is to occur). As such, a type of rolling consent will be needed, i.e. the person must be able to withdraw their consent and take off the suit/leave the VR when they want and refuse to use the suit. This is uncontroversial. Haptic suits, if they are considered treatments, are not treatments of the sort that are absolutely *necessary* for the users health, thus the user's wishes should be paramount.

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Assuming that use of haptic suits does not constitute research or treatment/therapy does not obviate the requirement of informed consent. Users are required to physically interact with the suit so informed consent is required. Also, much of the data that will be gathered will have clinical implications, e.g. could be used to gather data of medical significance.

It is clear that haptic suits straddle the line between medical devices and simple tools. However, when used in relation to PIDD, informed consent or proxy consent will be required in either scenario. We now go on to outline two requirements of informed consent in relation to haptic suits: *information requirements* and *voluntariness*.

7. Information Requirements

Developers of technologies such as *embraceID* will be required to present information in an accessible and comprehensible way. This will not be easy. There are three main elements that will need to be outlined. Firstly, developers will need to explain to users how the technology will be used, i.e. how they will put it on, etc. This concerns their physical interaction with the haptic suit.

Secondly, they will need to explain the nature of the VR/AR system to PIDD as best they can. It will be important to explain that the user will be in a virtual world but will encounter real people that they know *virtually*. Similarly, it will be important to explain that they will be receiving hugs from parents, and interacting with their real parents, who appear to present, but are not physically present.

Thirdly, they will need to inform users about data. Assistive haptic technologies that facilitate interaction between real people in a VR environment will generate massive amounts of data. For instance, it will be possible to gather genetic information (from sweat for example). Eye-tracking will be a feature of the device. It would be easy to include emotion recognition software as well. This has a number of consequences. Researchers will have the potential to gather medical information – meaning that they might create a doctor-patient relationship with the user. It is likely that the data will produce incidental findings, i.e. facts about the health of the users not germane to their online interactions.

Consequently, developers of haptic assistive technologies such as *embraceID* will need to specify what data is being gathered, where it is being stored, and how it is being secured. It will be necessary to specify whether medical data about the users is being gathered so as to determine whether a doctor-patient relationship is present. Stringent rules governing who has access to what data will need to be drawn up. Notas al final

The degree to which these issues can be explained and informed consent received will vary depending on the degree of the user's competency to understand the information. In cases where proxies are involved, it might be possible to provide more detailed information to the proxy than it would be to some users. It is possible that in some cases, consent will be required from both users and from proxies. If for instance, a user can understand that they will virtually encounter their parents by putting on a haptic suit, it will be necessary to obtain their consent. However, such a user may not understand the privacy implications of using the suit, in which case, proxy consent will be required.

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8. Voluntariness

Assuming these problems are resolved, haptic technologies such as *embraceID* could potentially face a problem in relation to the voluntariness of consent. While consent must be given voluntarily, there are various obstacles such as coercion, undue inducement, and the absence of a choice. The most pertinent in relation to haptic technology being used in the fashion being discussed is undue inducement, i.e. when the benefits on offer mean little attention is given to the potential risks.

PIDD are particularly vulnerable to this risk, especially in this scenario, where the inducement of "physical" contact with loved ones will be huge. It is possible that unscrupulous providers of haptic technologies or researchers could leverage the emotional needs of users in order to get them to agree to huge amounts of ancillary requests, e.g. giving up massive amounts of data.

Whilst many providers and developers can be trusted not to behave in such a way, there is no reason to suppose that this will be true of all providers. As such, government regulation will be required in these areas. Of course, ethical providers and researchers will be conscious of this potential and decline to take advantage.

9. Ethics of Care and Informed Consent

The discussion thus far, revolves around a model of informed consent based on autonomous individuals, or their proxies making decisions. In this model, informed consent is justified via an appeal to the moral significance of autonomy, understood as "rights, noninterference, self-sufficiency, self-direction, and rational control" (Osuji, 2018: 108). This liberal model of the autonomous individual has been challenged frequently in recent years, most interestingly from our perspective, from an *ethics of care* perspective. Ethics of care emphasises not the rational individual, but instead emphasises caring relationships.

Given that the haptic technologies under discussion are designed to facilitate relationships between people, the ethics of care perspective might be extremely useful. The ethics of care perspective sees autonomy as achieved through relationships with others, particularly family members. Nor does it view the contract model as an adequate model for relationships, noting that many relationships (such as that between parent and child) are unchosen and unequal in power. This focus on relationships has implications for informed consent as it "emphasizes a process approach to decision making wherein the input of relevant others to one's decision making is vital. This process approach requires the relevant others: family members, friends, relations, and others, be involved in the discussion and decision-making".

This is particularly pertinent to relationships between aging parents and children with special needs and to the use of haptic suits to facilitate these relationships. The use of haptic suits as ATs is designed to facilitate interactions in VR/AR with family members or loved ones. Moreover, in the scenario of more concern to us above, proxies will be required for users of haptic suits with moderate to severe intellectual disabilities. There will, therefore, be a broad overlap in this scenario between an ethics of care approach to informed consent, and the traditional liberal approach. Ethics of care emphasises caring relationships and looks for input

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from family members. The liberal individualist model will, when applied to PIDD, will also look to family members, who will be asked to act as proxies.

The ethics of care perspective throws up two intriguing cases. Firstly, by giving extra weight to family members, an ethics of care approach risks undervaluing a PIDD's perspective, particularly if they are reluctant. We can envisage a scenario where the parent is waiting in the VR/AR, but the PIDD is reluctant to put on the suit. The parent might be eager to see their child, and the carers with the PIDD know that the child usually enjoys spending time in the suit. The consequence of this is the position of the PIDD might be undervalued. Of course, this could happen in cases of proxy consent, but proxy consent places less importance on the family relationships and is somewhat more individualistic.

The second scenario is more speculative. The ethics of care emphasis on the importance of relationships for the individual. The individual achieves autonomy through relationships

10. From Haptic Suits to Experience Machines

If caring relationships are the central focus of ethics of care, some interesting implications arise from haptic technologies such as *embraceID*. Remember, when using such a technology, i.e. wearing a haptic suit and interacting with another person (a parent or child), the interaction takes place in a virtual environment. Each participant will see in the virtual environment a virtual representation of the other person – an avatar.

One major consequence of this is that deception becomes a very real possibility. It will be extremely difficult for anyone to determine whether or not the person they are interacting with – who, in the VR ecosystem appears to be a loved one – is in fact that loved one. If the system was to be hacked or otherwise infiltrated, anyone could interact with a user in the guise of their loved ones or friends. Obviously, this sort of deceit is something developers will have to guard against. Trust will be an integral value in these systems and will have to be built at an early stage. As haptic technologies facilitate intimate and personal relationships, simple cooperative self-interest will not suffice – trust will be crucial. Users will need to be able to trust that a) their privacy will be maintained, and b) the people they are interacting with are, in fact, the people they appear/claim to be. Whilst developers will no doubt strive to ensure that users can trust that they are interacting with the people they think they are interacting with, certainty in this regard is unlikely. Nonetheless, as long as there is a reasonably justified belief that the system is secure, users are likely to be content.

In terms of such technologies being used for PIDD, some there are some interesting implications. Those users that were never competent and are never likely to be competent will, as we have seen, require proxies to provide consent. As outlined by Graber (2017), such proxy consent ought to be based on best interests. The best interests of the users are, it is thought, going to be best served by being able to hug/have physical interactions with their loved ones. The ethics of care perspective also emphasises the significance of relationships, so for a PIDD the relationship with parents or loved ones.

Best interests, the significance of relationships, and the possibilities inherent in the technology pose a moral quandary. Even though PIDD have lower life-expectancies than average,

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many will outline their parents. Technologies such as *embraceID* offer a means of maintaining a semblance of the parent-child relationship in the event of the death of the parent. Some PIDD may not be able to grasp that a parent has died and would still wish to interact with their parent using the haptic suit. Despite the death of the parent, such interactions would still be possible. Extensive recordings could be made of the parent, which would be recreated in the VR/AR environment, or another person could interact with the user in the guise of the parent.

Obviously, this poses an ethical quandary – from the best interest perspective, a case-by-case approach would be required. However, in some cases, the benefits of having apparent interactions with parents might outweigh the harms. From the perspective of care ethics – if the relationship is paramount, then if the relationship continues via technology after the death of a parent, this is a benefit. In the specific case of using haptic technologies as assistive devices fro PIDD, we encounter a genuine variation of the experience machine. The fundamental question that must be asked by those responsible for PIDD who have access to such devices is whether it is acceptable to deceive users in these scenarios. Deceit of this sort – *well-intentioned* deceit – might turn out to play a crucial role in maintaining the autonomy of some PIDD (assuming autonomy is the value informed consent is supposed to promote). If the aim is to promote the happiness and contentment of the user, continuing the relationship in a virtual way is also likely to be desirable.

Neither approach can rule out deceiving PIDD in this manner altogether, though various objections can be raised. It might be argued that deceiving PIDD is never in their best interests. The consequentialist response will be that if psychological benefits arise, and outweigh the harms produced by the deceit (and PIDD might never become aware of this deceit), then the action is justified.

One might contend that deceiving the person in this way lacks respect towards the person, i.e. that the relationship could not be real – that it is a kitsch parody of the real relationship. This objection is harder to dismiss. Again, however, it is a principled objection and will run up again the consequentialist response raised above.

It is possible that the ethics of care perspective is to be preferred in solving this dilemma. Determining whether or not a relationship of an avatar of a now-deceased parent and a PIDD is permissible is likely to depend on the nature of that relationship and the role its continuance would play in the well-being of the PIDD. It is most likely to be determined on a case-by-case basis and will require the involvement of family members and carers in the decision-making. Indeed, the creation of an avatar that could interact with a PIDD plausibly will, at least initially, involve the parents or loved ones.

11. Conclusion

This paper has explored the question of informed consent in relation to researching and using haptic suits and VR/AR as assistive technologies for PIDD. This topic is especially interesting as haptic suits offer many benefits both to PIDD and their loved ones. However, the nature of the haptic suit being used in a VR/AR raises singular ethical problems

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when designed for use by PIDD. PIDD may struggle to understand the nature of the VR environment and of the suit. This complicates informed consent requirements during design, research and use.

Following a brief introduction to haptic suits and how they might be used as an assistive technology for PIDD, we focused on the issue of informed consent. Informed consent will be required if this technology is to be developed and used, but faces particular difficulties when dealing with PIDD. This is exacerbated by the fact that haptic suits will be used to enable PIDD to interact with parents or loved ones. In order to analyse these issues, we distinguished between informed consent in relation to treatment, research and the everyday. We then dug deeper into the topic of user involvement in the research of these technologies and how this would impact informed consent requirements. Following this, we looked at the use of haptic suits in treatment or therapy and in everyday use. We then outlined the problems facing researchers in relation to the information requirements of informed consent and then to the voluntariness requirements of informed consent. Finally we focused on an alternative conception of informed consent based on the ethics of care. Whilst this is promising, it raises interesting new dilemmas about using information gathered from haptic suits to facilitated PIDD continuing to interact with avatars of their loved ones in a VR/AR scenario even following the death of those loved ones. Assistive technologies are in this case offering us a snapshot of some of the novel ethical dilemmas of the 21st century.

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Notes

1. It seems clear that knowing whether haptic suits can help immobile carers communicate with distant children in care homes is valuable, that the research will generate the knowledge, that human subjects are required in the research, are important goals. We will assume that subjects will be selected fairly.

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