Disability Rights and Robotics
Co-producing Futures

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ABSTRACT
People with lived experience of disability, family carers, students and academics in robotics and social sciences came together as co-researchers to ask:
How can robotics technology support disability rights?
How can co-production research be developed to explore this question?
Using a knowledge café approach (Brown, 2001), we defined "ethical" research, generated questions, and tested robots. Co-production continued during the COVID-19 lockdown with the creation of a website, cartoon report, and international impact events. Institutional barriers prevented some members from continuing, which we discuss.
The themes highlight how robotics technology might create opportunities and relationships towards living a full life. However, control, use of personal data, and equality of access are concerns calling for co-production at the earliest stage of robotics design. We end with a reflexive account that draws on post-human disability studies that resist privileged views of "the future" and embrace a more fluid, relational discourse.

KEYWORDS
Disability rights, robotics, co-production, post-human, lived experience, COVID, family carers

1.0 Introduction

The Disability Rights and Robotics project brought together a team of young people and adults with lived experience of disability, family carers, students, and academics

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in robotics and social sciences. By the lived experience of disability, we mean the lived experience of having the label of learning disability, mental health, physical impairment, or chronic illness. By family carer, we mean the unpaid family carer advocating for their disabled family member. Our UK-based project set out to explore how robotics technologies can contribute to promoting disability rights. When considering "rights" we have used the UN Convention on the Rights for Persons with Disabilities, which states that disabled people have the same rights to everyday life choices, opportunities, health, and voice as everyone else (United Nations: Department of Economic and Social Affairs, 2016). The focus of our project therefore included rights to intimate life, social life, citizenship, and full inclusion in society.

This project was funded by a university internal funding scheme and governed by its protocol covering risk, secure data management, and permissions for sharing images. The ethics of this project were co-produced from the preparatory stages with the support of the university ethics committee chair. Ethical practice was a principal tenet of the project that, as we discuss, continued throughout the life of the project.

We aimed to produce a research agenda led by people with lived experience of disability and family caring and develop a co-production methodology. Co-production research intends to produce knowledge for public benefit that is practical and relevant and "is undertaken with people rather than on people" for socially just change that tends to extend beyond the project's life (N8 Research Partnership, 2016: 12). These principles support participatory experience-based research advanced within the social model of disability towards the realisation of civil rights (Oliver, 1990), and the call to de-colonise relations and prevent the "othering" of disabled people (Goodley and Runswick-Cole, 2012).

We begin by exploring conceptions of "disability", "the future" and "rights" as these concepts are debated. We outline and reflect on our knowledge café approach (Brown, 2001), the public involvement evaluation framework used, and the impact of the COVID-19 lockdown when the project moved from face-to-face to online working. For those members able to continue online, exponential energy was evident, and several creative, accessible online public impact events were co-produced. However, there was an abrupt end for those unable to access the project online, and we discuss our response to this context of digital poverty and normalcy (Sayce, 2021).

The three themes identified – "opportunities", "relationships", and "ethics" – were co-produced. The potential of robotics technology to enhance everyday life is explored under the theme of opportunities and relationships. The theme of ethics raised questions around control regarding design, purpose, use of personal data, and equality of access. We share our journey from trepidation and our questions about robot function for daily activities, to a more social and political focus on disability identity and rights-based innovation. The discussion of the themes, outcomes, and impact was co-produced. We finish with a reflexive account of the project that is situated in post-human disability studies. "Humanist formations are predicated upon some kind of bounded, rational, autonomous and sovereign human subject,

the post-human condition suggests something more expansive, relational and nomadic" (Liddiard et al., 2019: 2). This view resonates with the insights from disabled people's lived experience and perspectives from family carers, revealing complex and rich linkages with embodiment, technology, and environment.

1.1 Disability, Rights, and "The Future"

We begin with a critical view by drawing on disabled children's childhood studies (Curran and Runswick-Cole, 2013) and critical disability studies (Goodley, 2017), because thinking about rights and the future begins from early childhood. An uncritical view of disability would use and accept the dominant medical discourse, which focuses on pathologisation, impairment, and medical intervention in the form of rehabilitation and treatment (Goodley, 2017). This narrow focus, it can be argued, perpetuates inequality, marginalisation, and dehumanisation of disabled people and disabled children. Where the medical model of disability dominates, disabled young people continue to be discussed in terms of medical or welfare "needs" rather than as whole people with rights to a full life (Sayers, 2018; Wells, 2017). We therefore use the term "disabled" in line with the social model of disability (Oliver, 1990). Children's rights have gained attention and informed more active representations of childhood, but disabled children are rarely included in research regarding young people's rights (Watson, 2012). Disabled children's childhood studies consider disabled young people as having productive lives and futures with a focus on living life to the full, therefore challenging service-led discourses that limit discussions of their future to "independence skills" and "transition" to adult welfare systems (Curran and Runswick-Cole, 2013, Curran and Runswick-Cole, 2014, Curran et al., 2018; Runswick-Cole et al., 2018; Slater, 2013). Disabled children, young people, and adults have the right to a prominent voice and opportunities for inclusion in innovations in advanced technology and in re-imagining and shaping the future (Liddiard et al., 2019; Goodley et al., 2020).

From a critical disability studies perspective, idealised notions of the future from the Global North are arguably problematic. The "future perfect", with its normative life span expectations, reflects and justifies privilege accumulated through continuing histories of racism, patriarchy, ableism, and heteronormativity (Rice et al., 2017). Rice et al. (2017) therefore suggest such a view of the "future perfect" is to be resisted and they favour fluid, multiple views in which the future can be imagined in the present.

We define robotics technology within the framework of the post-human discourse as acknowledged by Haraway (1991: 150) – "we are cyborgs". Cyborgs are hybrid special beings both organic and synthetic, human and machine (Haraway, 1991). Many within Western society have close relationships with smartphones and other forms of technology, including robotics technology. Within the field of assistive technology there is some debate as to whether an innovation needs to be "universal" or "assistive". There are different models of assistive technology; however a commonly held ideal is the focus on "improving" a disabled person's functioning

and capability (Encarnação et al., 2017). We draw on the post-human discourse to challenge and disrupt this distinction as the concept of the cyborg invites us to think more deeply about what inclusion means as a practical and cultural experience. This engagement with the post-human is important as it offers connections between rights, technology, and experience. Disabled people have historically had particularly close relationships with technology related to accessibility, engagement, and interaction towards living a full life (Williamson, 2020). It is therefore essential to value and recognise the long-standing expertise in the field of digital accessibility, and collective advancement of inclusive modes of working (Goggin, 2016). Without inclusion being prioritised, technological innovation can be individualised and fail to challenge systemic barriers, an issue we return to in our discussion. It follows that for our project, a co-production methodology was crucial to recognise this expertise drawing from lived experience.

2.0 Co-production Inquiry

The co-production methodology was designed by the initial academic members of the group, around a knowledge café approach (Brown, 2001) with an openness to developing the method during the project through feedback activities and a framework designed to evaluate public involvement (Gibson et al., 2017). The knowledge café approach aims to generate, validate, and promote knowledge for action created by the co-researchers (Brown, 2001). Knowledge cafés use five key principles: to create a hospitable space, explore questions that matter to the co-researchers, connect diverse perspectives, listen together for patterns, insights, and deeper questions, and make collective knowledge available to the group (Brown, 2001: 4). Preparation is a key stage of any co-production process for building trust in relationships and establishing a reflective and flexible approach (N8 Research Partnership, 2016; Social Care Institute for Excellence, 2013). To create the hospitable space needed for the knowledge café, we took steps towards building relationships as described in the following section. The second principle of exploring questions that matter begins with the conversations between co-researchers sharing their lived experience and forming their research questions. The activities planned for the knowledge cafés aimed to deepen the inquiry and generate knowledge. One of the methods used to capture knowledge was to engage a cartoonist in an advocacy role. The cartoonists' method was to clarify what each person was aiming to communicate, identifying their key ideas and subsequently producing the cartoon, which was checked and confirmed by the group.

Three cafés were planned at the university robotics lab to include meeting the robots Pepper and Double, trying out the "driverless car" simulator and the sensors and other robotic technologies in the Assisted Living Studio. However, only the first café took place before the first COVID-19 lockdown, when the project went online. The café principles and processes continued through to the design of the impact events.

2.1 Building Relationships, Forming the Co-production Team, and Generating our Ethics

The academic members of the co-production team came together from social sciences and robotics to produce an information sheet that set out the project aims, method, and expected outputs along with an Easy Read version of The Convention on the Rights of Persons with Disabilities (2009). To encourage co-production, it stated that the information sheet was an outline, and that the co-production team would have the opportunity to shape the project.

The process of building relationships began with the co-ordinator approaching groups in their existing networks in social work and sociology, robotics, and public involvement. Young people with lived experience of disability were approached from a further education college and support for the young people was arranged through a user-led organisation that had contributed to a previous peer research project that asked disabled young people about their hopes and dreams (Jones et al., 2018; Curran et al., 2021). In that project the young people stated that they disliked the term "disabled young people", preferring "young people", as they expressed the same hopes and dreams about their future as non-disabled young people, so the term "young students" will be used henceforth. The cartoonist from the previous project was engaged for café 2 and 3 in an advocacy role to ensure the young students' voices were captured in an otherwise adult group. The cartoonist also joined the online work ensuring all key messages were captured and illustrated. The co-ordinator invited adults from the social work 'Hub Group', an established group contributing to the social work programme bringing their lived experience of disability, mental health, learning disability, and family carers. Students in robotics and social work were also invited to join.

All groups were invited to attend an initial meeting that outlined the project and to develop an ethical framework together. This meeting was held at their location and run as a mini café for potential members to gain experience of the approach in order to make an informed decision as to whether to join. The meeting began with a discussion about what "rights" meant to each person in their everyday life. Then participants were asked what they thought an ethical project should be like and their ideas were recorded in a word-cloud (Figure 1). The words appear in varying sizes related to frequency of use. The words such as personal safety, informed consent, and data security reflect the standard considerations required by university research ethics committees, but the inclusion of access requirements, space and pace, and the concern for feelings reflect deeper ethical awareness from lived experience. Ethics were defined by co-researchers as continuous and developing practices with multiple and necessary layers. Ethical approval from formal bodies such as university ethics committees usually include "lay members"; however research "subjects" would not routinely be involved or privy to the committee discussion. Conventional

Figure 1 Co-produced ethics word-cloud

"approval" can therefore reflect "colonial" relations constructing otherness and vulnerability that Goodley and Runswick-Cole (2012) warn us against. This early engagement in conversations about ethics illustrates the value of expertise from experience and provides a co-produced resource that can inform future research.

The membership of the co-research team is shown in Table 1.

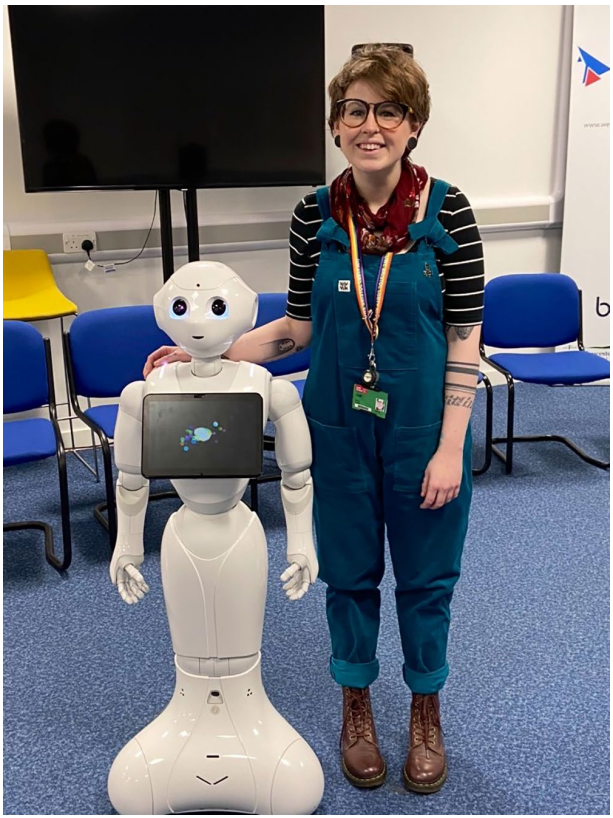
Table 1 The co-research team members

Groups with abbreviations	Number of members
Young students from college (YS)	5
BSc Social Work Students (SW)	4
Hub Group - people with lived experience of social work (HG)	5
Masters in Robotics students (RS)	4
Social Science Academics (SS)	3
Academics in Robotics (RA)	3
Cartoonist ©	1

3.0 The Knowledge Café

The whole co-researcher team first met together at Knowledge Café 1, held at the university robotics laboratory. Social work students and academics arrived early to prepare the space. They posted directions and a project flyer on the doors to welcome those new to the campus and displayed the ethics word-cloud to indicate that their contributions would be valued. Tables were laid with drawing materials, fruit, refreshments, and flowers. The menu on each table set out the order of the day's activities, which included: Welcome to the Knowledge Café, Sharing experiences of using technology, Generating questions, Deepening the enquiry by meeting the robots, Capturing the knowledge generated, Evaluation of the Knowledge Café. Robotics academics demonstrated how the robots worked to those who had arrived early, so that when the other members of the team arrived, they were prepared to introduce them to the robots (Figure 2). Co-researchers were seated together in their groups (social work

Figure 2 Becoming co-researchers



students, robotics students, Hub Group members, young students from the college, and the academics were seated on different tables in a facilitative role if needed), to maintain familiarity in an unfamiliar setting and be introduced to the Knowledge Café aims and menu.

3.1 Beginning with Experience and Developing Questions that Matter

Everyone was encouraged to share their experiences of rights and robotics and, from that conversation, to form their questions writing on the tablecloths, drawing, and using sticky notes for sharing with the whole group (Figure 3).

The young students were interested in what the robots could do, how they worked, what they can learn, what is in their dictionary, how they will upgrade, how long they will last, and whether they are accessible. There were also comments about whether it was possible for a student to decorate their robot so it might feel like it is theirs, and whether robots have feelings. Regarding the robots' potential limitations, there was a concern about whether the robot would understand someone who uses speech-assistive software to speak. Hub Group members had questions about functionality framed around human rights about the potential to make life choices viable. Their concerns were around privacy regarding access to personal data and their preference for a human carer. Social work students had questions about availability, accessibility, cost, and inequality, and having the right to refuse a robot as it may be potentially intrusive.

The robotics students brought their knowledge and understanding of engineering and were interested in the gaps between robot functionality and people's expectations. They raised questions around humanoid design, intelligence, robot appearance, and the importance of the robot understanding users and vice versa.

> *What is the trade-off between engineering spec and features that are helpful to people? People seem to desire a robot capable of fully understanding them, and at the same time, they seem frightened by a robot that is too intelligent* (RS).

The robotics students responded to the concerns raised around the limitations of robot function, explaining how robots can learn to use particular forms of communication such as sign language. However, the robotics students did not see the robot as something people should become attached to, as technology is constantly updated. Their questions revolved around how robotics could support disabled people around vision, hearing, speaking, and helping children learn. Here we identified that the robotics students were primarily focused on impairment and rehabilitation. This focus led to a discussion around language and terms associated with the medical model of disability. Social science academics and co-researchers with lived experience explained the social model of disability (Oliver, 1990) and its focus on experience-based social action:

> *If we could change oppression, words would not be so important* (HG).

The robotics students expressed their appreciation of the expertise of those with lived experience, and co-researchers from the different groups agreed that they

Figure 3 Beginning with experience for questions that really matter

wanted to continue discussing language and learn from each other. This exchange valued the range of expertise in the team and at the same time formed connections for a critical approach building confidence for further critical conversations.

3.2 Deepening the Inquiry

After the co-research team composed their questions, they moved into an open space to engage with the robots: Double the telepresence robot, and Pepper the social interaction robot (Figure 4). The first robot that was demonstrated by one of the co-researchers was Double. Double operates through a screen on an adjustable stand attached to a Segway wheel. A person anywhere, who can connect to the internet, can use their device (computer or smartphone) to control Double's movement and to interact on screen with people by using the in-built camera, microphone, and speakers. As the co-researcher drove Double round the room interacting with different people, people in the room responded and chatted to the co-researcher on the screen (Figure 5). Several of the young students asked where the co-researcher was speaking from and went to find them in the corridor so they could also test drive Double. There was a sense of delight in discovering they could be outside the room and, using Double, feel as if they were inside the room speaking to their peers.

Figure 4 Demonstrating Pepper

> *My face and voice appeared, I had a robotic body, and I could move. I felt the coolness of the corridor, and yet I was in the café again. I moved around speaking with my co-researchers, some of whom were previously uneasy, suddenly a buzz of energy and excitement moving close to the screen. Double was no longer a foreboding inanimate robot or an object of fear but a catalyst of curiosity. Before long, I heard the cheers of my co-researchers joining me in my lonely corridor keen to operate Double. I held the laptop steady as my teammates pushed the controls, and I felt like I was glimpsing the future. Where if even apart, we can still be a part of creating, sharing, and learning together* (SS) (Curran et al., 2020).

The co-research team reported that using Double felt like a more inclusive experience than using video calls due to the control over its movement in the room. The co-research team identified further possibilities; "Could telepresence read my post to me?" (HG), working out that by putting their letter in front of the screen, the person using their device could read it out.

When Pepper the social, humanoid robot was activated by one of the co-researchers, the atmosphere changed again (Figure 6). The warmth with which co-researchers greeted the robot, asked it questions, and wanted to touch the robot, was immediate. The co-researchers wanted to know how Pepper functions and learns, what its hands can do, where it gets data from, who is maintaining Pepper, and who can access the data Pepper collects. The young students said that having Pepper around to talk to as a buddy or a guide at college would be good. However, Pepper did not function as expected when many people tried to interact, and the robotics academic had to mute Pepper in order to respond to questions.

The co-researchers raised concerns about who could access personal data 'learnt' by the robot. The team discussed the importance of choice when sharing data, knowing and choosing what in particular is shared, with who and for how long. Decisions around sharing data need to be easy to understand, and it also needed to be clear who might be able to support decision making. We learnt that Pepper has limited internal memory capacity and uses cloud storage, hence the data Pepper collects is not stored inside Pepper; it is not therefore a simple case of choosing not to plug Pepper into a computer to control data sharing.

The robotics academic explained safety in terms of building safeguards into the robots' function:

> *Designers have stopped harm like its hand can't squeeze you and hurt you. If it were available to customers, it would have safety built-in; you could not make it do things it was not programmed to do* (RA).

The robotics academics also explained infra-red cameras can be used to show a person moving; for example if they were up awake at night, and this could be of use to staff in a care home. This image would not show the specific details or face of the person, in order to protect their security and privacy. However, the carer and disabled members of the team were not reassured by these technical or service-led explanations, and control of data continued to be a concern, as discussed further below.

Young students' deeper questions led to suggestions for design improvements and knowledge for action. Pepper is relatively small at only 120cm high, and the robotics academic explained that it was designed at this height so as not to frighten, but co-researchers who were much taller wondered if it was too small. Young students asked if Pepper could go upstairs; however, the robotics academic explained this was not possible, so there is a possibility that two Peppers could be needed. Pepper could not understand or respond to a co-researcher who used speech assistive software to speak, which meant they could not ask Pepper questions as others did, and thus in this Knowledge Café they experienced exclusion without any warning. The robotics academic explained Pepper could be programmed to learn how to communicate with those who use speech-assistive software, but this was not a standard function. On the topic of accessibility, the robotics academic explained that Pepper could also learn to recognise sign language/s and that people with vision impairments can have a sound played to know it is on. This exchange regarding functionality and accessibility illustrates assumptions and the impact of those assumptions made in robotics design around what were to be standard features and what would be "learned" for each

individual. As communication is a primary function for Pepper, being a social robot, we argue a standard feature should include various communication formats, particularly those mentioned. This latter experience of exclusion raises a query concerning our first aim. How can the designers build in accessibility features as a required standard and the potential to learn where there are individual-level preferences? It also linked to our second aim; how might we have asked about the accessibility of the robots ahead of the project? This experience was a helpful reminder that co-production could be an excluding experience and potentially harmful, which illustrates the importance of having people with lived experience fully involved at the very start of project planning to introduce questions regarding accessibility.

3.3 Generating Knowledge for Action

In this knowledge generation stage of the café, the young students left the café and later shared their reflections noted on the journey back to college. The other co-researchers returned to their tables to discuss their experience of engaging with the robots.

The young students initially had mixed emotions about robots and meeting people they did not know. They felt scared, anxious, and confused by the robots and not sure what to expect.

> *When I first saw them, I was unsure […] It was all new* (YS)

After having met the robots, their views changed:

> *I feel happier now. I know what to expect, and it's ok now.* (YS)
>
> *Looking forward to seeing the robots again now.* (YS)
>
> *The more I saw them, the more it was ok.* (YS)
>
> *I liked the robots.* (YS)

They noted that Pepper the robot was easily distracted and did not work well in busy areas and with big groups of people. The young students gave examples of how Pepper could be of use:

- To provide reminders to do things
- To talk you through recipes
- To assist you with washing up and cleaning
- To help you tidy your room
- To remind you to pick up your socks
- To help you with your spellings
- To help you put your clothes away

For the Hub Group members, there was a strong emphasis on the need for these robots to be person-centered and designed ready to communicate in many different ways with age-appropriate language, using preferred words, and for there to be choices available around the use of language (e.g. without long phrases or sentences):

> *Can robots understand "broad" accents?; Perhaps the robot needs to ask, "How do you want me to speak to you?" to avoid upset* (HG)

> *This kind of co-production is important, so the words we choose are there from the beginning of design* (HG).

Members with experience of using artificial intelligence software such as Siri and Alexa saw how Pepper could act as a companion:

> *You could share issues and have a companion. It does not judge* (HG).

Pepper was deemed useful for daily activities to support independence and for emergencies if a person was unwell or had a fall, but felt that it may have difficulty predicting harm that relied upon humans to identify. There were queries regarding privacy, safety issues, and whether Pepper could be turned on and off at home or by a carer. Who was in control of the robot and its purpose mattered, given the potential for oppression. The whole group nominated this Hub Group member's comment as the quote of the day:

> *Co-design is essential – without it, it is pointless!* (HG).

Social work students checked out the cost, availability, and training online and queried whether the government would fund these robots. They shared the concern about privacy and added the risk of hacking data. The assumptions made about the gender, height, and age of Pepper were discussed, but it was also seen as a non-stigmatising form of support:

> *[I]t's subjective, but I would like to be seen with a robot in my home by friends – it's cool and more appealing than a carer or equipment* (SW).

Students and academic members of the team who also had lived experience of disability extended the conversation from home to school, leisure, and work. With Double, the telepresence robot, it would have been possible to "attend" school from home, and really feel involved in group work with their class, and at work, it would be possible to attend meetings and conferences overseas without the various risks of travel.

> *The telepresence felt like being there without being there* (SS).

The co-researchers reflected on the café inquiry experience, highlighting the change in the room on introduction to the robots:

> *We went "whoooo" when we saw the robots; we lost our anxieties and suspicions, it was like Christmas – opening toys for grownups, we had a go, asked Pepper questions. I now saw a robot – had to see it to believe it. Everyone had a go themselves, had to touch* (SS).

3.4 Co-produced Review of the Methodology

The second aim of this project was to develop our methodological approach in response to co-researchers' ideas, evaluation, and feedback. Our team used an evaluation tool specifically designed to evaluate public involvement (Gibson et al., 2017). The four questions below were customised for our project:

Are there many ways to be involved?

Have we been flexible in how we work with you?

Have your concerns been heard?

Have you had a weak voice or a strong voice?

Co-researchers were invited to place a sticky note with their comments on large paper on the wall for each question, along poles of negative and positive experience accordingly, and the young students' responses were noted by their supporters on the journey back to college. Positive feedback for the café included the benefit of getting to know different university departments, being hands-on and interactive with reasonable time to try out the robots, asking questions, and being heard citing the conversation about the need for care with language, the set-up of the café and facilitating discussions. Some members felt anxious and unsure about what they would be doing in an unfamiliar setting, not knowing everyone, and not seeing a real robot at the start of the café. At times there were too many conversations happening at once, and it was not easy to hear. It was suggested that introducing the robots in a familiar setting and starting with small groups of three or four people before joining the larger group could be a good solution. This would reduce noise levels, and co-researchers may feel more comfortable, improving concentration and giving space for thinking.

The co-research team appreciated the advocates' and college teachers' roles providing familiarity and supporting the young students in preparation for activities and discussion. Acknowledging these vital roles is essential in planning accessible future activities. The co-researchers valued the use of the evaluation tool:

We liked to be asked about our participation – we think it is good practice to ask us (HG).

4.0 Online Co-produced Analysis During the COVID-19 Pandemic

The COVID-19 pandemic led to the immediate closure of the university and the young students' college, and two further Knowledge Café days that had been planned to test different robots and visit the assisted living studio could not take place. The project co-ordinator contacted the team to explore online ways to continue our inquiry, analysis, and impact events. Unfortunately, the young students could not participate further as college staff were not available to support or work through the accessibility of home-based digital resources for the remainder of the project. Other co-researchers faced the demands of online professional practice placements, completion of new online study, child-care with school closures, employment changes and the additional demands due to the impact of COVID-19 lockdown measures. The co-production team's work continued with four Hub Group members, two social work students, two robotics students, and four academics in social science and robotics.

In our online meetings the co-production team identified three interlinking themes: Opportunities and control of purpose, Intimate rights and relationships, and Disability rights and ethics. These themes were action-orientated and clearly shaped by the experience of the COVID-19 pandemic, and informed the key messages and questions produced for further research.

4.1 Opportunities and Control of Purpose

Members drew on their lived experience to manage the new context of the pandemic and to identify how robotic technologies might assist. The exclusion of disabled people led to questions regarding ableism rather than impairment. For instance, employers found ways of providing the flexibility and home working long sought by disabled employees (Ryan, 2021).

Students in robotics commented on the importance of working with communities in design, stressing the need to find out how people feel as "feeling is closely linked to purpose" (RS); whether robots generate fear or appeal will determine their value or result in resource waste. For those with lived experience, having control of the purpose and application was key. For instance, self-monitoring could be empowering if an individual wanted to self-motivate around their exercise goals. Or it could save the person effort when wishing to give their medical team the data they chose to share, such as their sleep patterns captured by robotics sensors.

Controlling the purpose and the degree to which robots could "learn" and respond to the person's preferences was key to the use of robotic technology. The robotics students and academics met these ideas with openness:

> *Robotic technologies are early in design so they can be like a person, a box, taller and so on; there is no need to stick to what there is now* (RA).

4.2 Intimate Rights and Relationships

Many co-researchers commented on how the COVID-19 measures had raised their awareness of the value of social life. Robots could assist communication, sustaining relationships for people shielding for long periods with carers not being able to visit adult children in care settings, by providing visual access to the parents' home or school and work. When COVID-19 results in many changes of carers, Pepper might be able to be the constant and be used to train a new carer with pre-agreed prompts. A good carer, we heard, is one who is responsive and wants to know the person they are providing care for very well, and is always learning, curious, and questioning. When there are many new carers, poor communication and panic-based care was experienced by some family carers, whereas a robot trained by a person who knows them well could result in continuing support. If Double was available in hospitals and care settings where relatives or advocates could not enter, they could have that greater sense of "being there" than a phone or video call provided. As the lockdown measures eased, the return to pre-COVID-19 routines could be daunting. Double might be beneficial to bridge home and college or home and work. If young people are away from school for periods of time, then their peers

and teachers can see them and not forget them, and the young person has a better opportunity to keep up with social connections as well as schoolwork. Pepper could be a potential guide or buddy that would be beneficial to have around the house; even if spending time with friends was limited by restrictions, Pepper could provide consistent companionship.

4.3 Disability Rights and Ethics

The discussion of ethics ran throughout the project and continued into the outcomes and impact stage with a continued emphasis on accessibility. Pepper was seen as a source of personal and social support, and Double the telepresence robot was seen as inclusive by facilitating participation. However, all groups in our co-research team were concerned about the ethics of access, security of personal data, and the control of technology.

For robotics technology to be accessible, it needs to be stigma-free and easily available, not an out of reach luxury for the privileged few or stigmatised as "specialist equipment" rationed through professionals' assessments of eligibility for state-funds. The use of robotics technology could be viewed as unwanted surveillance; however, it may offer security for someone if such surveillance may protect someone from risk or harm. The person using the robotic technology and their carers would be crucial to the interpretation of safety and harm.

People with lived experience of disability and family carers are key to challenging assumptions, which is vital for inclusive design. In designing a robot without starting with the end user, there is the potential to create something unwanted, and unhelpful, like a robot-guide dog. As one of the Hub Group members explains:

> *Do not assume people with a sight impairment want a guide dog or that it would fix everything. Instead, ask, "What do you want the robot to do for you?"* (HG).

The co-production process can ensure that disabled people and family carers can shape the research agenda, and to maximise the control of technology in terms of its use and purpose.

> *Robots are about practicality, ethics and relationships. It is assumptions that are dangerous!* (HG).

The co-research team produced a short report through online meetings (Curran et al., 2020) and worked with a community cartoonist who captured the project journey, confirming what the team wanted to express and ensuring ideas were fully conveyed. The key messages were around the importance of:

- Disability rights
- Driving robotics design
- Equal access
- Communication
- Privacy
- Feelings

Co-production is vital for a rights-based approach that centers lived experience in the development and design of inclusive technologies, to break with the historical stigma associated with "needs based" provision. The priority questions for further research created through the project combine robotics design, co-production, pedagogy, and policy as follows:

- How will robots be ready to communicate in the full range of accessible formats so potential users are not excluded?
- How can engineers work with communities around the feelings and purpose of robotics?
- How can robots add to students' learning and social experience in education settings?
- What are the existing ethical and legal standards on robotics? Are these adequate for inclusive, accessible design?

5.0 Co-produced Impact and Outcomes

A range of impact events included participatory cross-disciplinary and public opportunities to share the project, and a website was developed to engage a wider audience in our key question around disability rights and robotics (Disability Rights and Robotics, 2020). The website presents an archive of all our impact events, resources created, and information about our team. As a part of UK Disability History Month 2020, an online telepresence tour of the assisted living studio at the university robotics lab was shared and the public were invited to a Knowledge Café opening with our primary question "How can robotics technology support disability rights?" The co-production team brought attention to accessibility of impact materials and events. The publicity for the event included access arrangements; advance materials were provided (a recording of the tour and a copy of the script) and BSL interpretation, live captioning, and audio description were in place during the event. During the event, accessibility measures were explained, and participants were asked to maintain a slow to medium pace, which facilitated lip-reading.

A survey was used to evaluate the telepresence guided tour, and the café evaluation took place at the end of the event using the public involvement framework now developed as an online live tool (Gibson, 2017). The evaluation data was generally positive, but the review revealed times when people felt overloaded and thereby discriminated against. The main lesson was not to adapt and add access arrangements, but to move away from a presentation format as far as possible. This learning led to a cross-disciplinary commission to develop guidance on accessibility for university online public events (Disability Rights and Robotics, 2020). This involved the Hub Group members on a paid basis. N8 Research partnership (2016: 12) state that co-production often has practical outcomes that are realisable when stakeholders come together and learn about their different contexts, often continuing beyond the life of the project. Questions raised around how robotics could be used in work informed a successful bid for a teaching and learning project piloting telepresence

in social science teaching that will be reported on the project website. The social science academics also contributed to a research funding bid, led by the robotics academics, allowing disabled people to use robots to access galleries and museums, in a move towards improved wellbeing in the context of the COVID-19 pandemic.

Our team hosted a half-day workshop at an international robotics conference, coordinating with colleagues from the Global South and North who were using co-production to explore technology. The different concerns of the Global South and Global North identified in our project became the prominent agenda for the next phase of our work and informs the post-human theoretical reflection presented below. We also ran an interactive event at a local Cubs group, engaging younger children in our enquiry, and will be offering the café to the young students' college.

A university certificate of achievement was given to each team member as co-researchers in this project.

6.0 Connections with Post-human Theory

As the above discussion was co-produced, we finish with reflections that re-visit the post-human theory and include the perspective of the social science academic with lived experience of disability. There are many assumptions held by society regarding the disabled people's bodies that do not capture the vast diversity this population encompasses (Goodley, 2017), including the consideration of the important relationships many have with technology (Shildrick, 2002). In addition, Haraway's (1991) 'cyborg' has an active blurring of the distinctions and divisions between organic and synthetic material.

The co-researchers brought the experience of technology and robotics or "smart" technology. Some had the experience of "care" and recognised risks of being "done to" rather than being in control. Our initial questions were on how robotics could assist with daily activities defined as domestic routines; however, the project reflects a shift from concerns around robotic function and daily activities to ethical considerations and identity. This shift can be read as a move from the medical model of disability and its humanist assumptions towards a post-human construction illustrating the rich and creative lives of disabled people and family carers. The shift from anxieties to inquisitive engagement and "playing" with Double and Pepper was a turning point and moved us into the conversation around identity about "being there without being there." However, we show how oppositions such as "independent/dependent", "human/machine", and "carer or professional/cared for" operate in conjunction as a dynamic. This analysis allows us to re-imagine the contribution of robotics to disabled people and family carers regarding a full life.

Initially, we perceived the human and the robot as distinct entities. For example, the human carer could have unique capabilities for ethical discerning care, whereas robot care remotely managed could be degrading and isolating. We also heard of human carers subjecting the cared for to their anxieties in contrast to the robot signifying a "cool" and reliable alternative. Our engagement with the robots led to the transgression between the distinction of human and robot. As a result, a flexible,

mobile, and relational cyborg view emerged, as captured in the autoethnographic reflection in Figure 5. Our team valued robotics technologies to make life easier, so rather than seeing these as oppositions, we might extract "daily activities" from the rehabilitation discourse and re-imagine them as significant aspects of personal and intimate life, with the contribution of robotics technology being both assistive and expansive.

DeFalco (2021) points to a parallel with the low status afforded to carers assuming that the caring role is limited to daily mechanical tasks – machine-like work that a robot could undertake. Here we have re-imagined the role of the carer and the robot – the person-led starting point brings the creativity and sophistication needed for full valued versions of life and full valued versions of care. DeFalco (2021) points out that people may claim "the machine" itself is neutral, but the robot is inseparable from the human designer and funder.

Figure 5 Interacting with Double

Figure 6 Interacting with Pepper

6.1 Cyborg Reflections on the Future

Within this project we have explored how robotics technology can support disability rights, which has led me to thinking about other forms of technology and how this relates to my understanding of what it is to be a cyborg. I have had a liver transplant, a procedure only made possible with technological innovations in the form of life-supporting machines and biological technology in form of medications to support my body's relationship with the grafted organ. It is such technology that has supported my very existence, and without this technology my right to life would be forfeit.

I now find myself reflecting on how I understand and work with different concepts of disability and how they relate to me as a disabled person who has been shielding throughout the pandemic, whilst completing this project. Currently I am not able to access the university campus due to being immunosuppressed following a solid organ transplant due to the level of risk posed by COVID-19. It is as if there is the drawing together of the oppositional ideas of the social model, medical model, and human rights convention as discussed above. This project has provided the opportunity for me to use robotics technology, particularly Double the telepresence robot, which allows me to be within a space I am not able to access and to function as an academic.

It feels like my imaginings of the future and inclusion are being realised in the present; through the use of Double I can really be there without being there. The experience of using Double supports my right to work, my right to a social life, and my right to access; it supports me to remove barriers to meaningful inclusion and allows me to functionally be in a space. This project has led to a new pilot project testing telepresence teaching in higher education as a reasonable adjustment for disabled academics. Reflecting on my experiences of exclusion from classrooms and spaces throughout my education, I feel strongly that disabled children and young people could have further opportunities to realise their right to education through this technology.

The concept of the cyborg invites an opening to ideas around the possibilities of robotics technology, which is why co-production is so vital, as people's identities, expression, rights, and lives can be formed around these creative relationships with robots.

7.0 Conclusion

Disabled people continually adjust to accommodate non-disabled people's attitudes and social barriers, and the technology that can be used in that form of oppression. The leadership role of co-researchers with lived experience is vital in shaping the research agenda sustaining a critical approach that highlights socioeconomic inequality and oppression. From Kath et al.'s (2019) position, the post-human perspective, assistive technology, and the cyborg are not about fixing a person or making superhumans with super robots but improving the context – it's about inclusion. It's about keeping ethically connected, being part of an assemblage of embodiment, technology, and environment (Kath et al., 2019: 679). Therefore, it follows that disabled people should be at the forefront of leading the narratives around technological innovation, because if these innovations are being made "for us" but "without us" it is pointless. And without us, there is a great loss of expertise, experience, and a wealth of knowledge.

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