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Distributed Participatory Design: The challenges of designing with disabled musicians during a global pandemic

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This article addresses the OS themed issue “Socially Engaged Sound Practices” with the following thematic topics:
Distributed authorship; Collaborative approaches; Shared listening; Socially engaged practices

Keywords: distributed practice, distributed participatory design, disability, inclusion, accessibility, collaborative design practices, socially engaged practices

Abstract
The global COVID-19 pandemic has been an extraordinary situation. Social-distancing has impacted the vast majority of people, reorganising society, physically separating us from friends, family and colleagues. Collectively we found ourselves in a distributed state, reliant upon digital technologies to maintain social and professional connections. Some activities can translate unabated to a digital medium, with benefits, such as the convenience inherent in many online shopping and banking services. Other activities, particularly those which are collaborative and personal, including music-making or design, may need to be re-framed and re-thought due to the absence of in-person contact.

In Northern Ireland, the Performance Without Barriers (PwB\(^1\)) research group works with disabled artists from the Drake Music Project Northern Ireland (DMNI) to identify ways in which technology can remove access barriers to musicking. Since disabled people are experts in their unique lived experience of disability, they must be involved in the design process, an approach known as participatory design. Many of us are still adjusting to the new normal, only beginning to understand the impact of distributed digital living. In this article, we examine how the work of PwB has been affected, changed and adapted during the pandemic, expanding ideas of distributed creativity to the

\(^1\) performancewithoutbarriers.com
notion of distributed design. The authors formalise the concept of distributed participatory design, an approach which classifies PwBs current research activities in the area of accessible music technology (AMT) design and improvised musicking. Consideration is given to the impact distribution has on degrees of participation.

1. Distributed Creativity

In the context of inclusive music, the nascent notion of distributed participatory design traverses pre-existent, established forms of distributed creativity (Schroeder, 2013, 2016; Glăveanu, 2014; Clarke and Doffman, 2017), including distributed listening and distributed performance practices (also referred to as network music or telematic music\(^2\)). A collated resource with over 700 articles, recordings, theses, webpages and more on networked music performance has just been launched by Rebekah Wilson\(^3\).

The COVID-19 pandemic rekindled a collaborative, communal and creative spirit in many people, re-awakening\(^4\), and indeed re-inventing, distributed performance practices. COVID-19 stimulated active, performative, distributed engagements amongst diverse people and between people who, before the pandemic, may have never made music together. At the same time, listening became a socially shared and distributed phenomenon, as something that happens with others, where listening is reciprocal. Distributed listening, actively challenges our ears to both perceive sounds nearby, and at disparate, remote sites. Schroeder has referred to this listening as a type of sonic flânerie, where our ear is sauntering across nodes. Listening becomes an exploratory activity, a process of familiarising oneself with the sonic environment. Akin to the flâneur who strolls through the city, openly accepting the possibility of becoming lost in the streets; the listener can become gently lost in the sound world\(^5\). Such mutual, social, creative exchanges were especially visible, and indeed audible, during the pandemic as people tuned in to each other and their living spaces, via network platforms. While most of us were disconnected physically, our shared listening experiences challenged us to tune into others and ourselves.

2. Distributed Musicking During the Pandemic

Economies worldwide froze, as a result of efforts to protect public health. In the UK, to meet government social-distancing guidelines, many workers were prohibited from entering the workplace. The consumption of goods, services, and the arts were constrained. High streets, public venues, bars, cafés and restaurants were deemed unsafe, and could not remain open. As a result,

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\(^2\) This paper will not elaborate on the area of network performance / telematic performance / distributed creativity, as this has been done in plenty of other writings, and Ximena Alarcón recently provided a succinct overview of the history and practices of telematic performances (2020).

\(^3\) latencynative.com/zotero

\(^4\) Musicians have been engaging in the making of music over networks for a long time. However, before COVID-19, this practice tended to be hidden in the concert/research spaces of academic institutions.

\(^5\) Honoré de Balzac described flânerie as ‘the gastronomy of the eye’. Schroeder (2013) imagined distributed listening as a ‘gastronomy of the ear’, savouring each sound coming from close by as well as from disparate places.
many performing musicians lost multiple income streams overnight\(^6\). Creative work is precarious, even under more normal circumstances. The performing arts sector is already disproportionately affected by problems of inequality, lack of diversity, and poor mental health (Tsioulakis and FitzGibbon, 2020). Such factors primed the pandemic to be particularly challenging for performing artists on several levels. This article focuses specifically on the impact on disabled musicians. However, first, the discrimination faced by disabled people in the provision of healthcare is highlighted.

During the first wave of COVID-19 cases, the UK government became concerned that the National Health Service (NHS) could be overwhelmed. A shortage of medical staff, hospital beds and equipment was a possibility. The British Medical Association (BMA) produced guidance on the potential rationing of NHS resources; if the need arose. Patients with the best prognosis received priority, i.e. those who were younger and healthier (Ryan, 2020). This policy contradicts Article 25 (1) of the Universal Declaration of Human Rights, stating that everyone has a right to medical care:

‘Everybody has the right to a standard of living adequate for the health and well-being of himself and his family, including... medical care.’ (United Nations, 1948)

After threats of legal action from disability groups\(^7\), the National Institute for Care and Health Excellence (NICE), rapidly backtracked on advice given to the NHS. Originally, NICE had suggested that learning-disabled and autistic people should score high for frailty, essentially deprioritising their treatment. Updated information on the use of the Clinical Frailty Scale was provided on 31 March 2020\(^8\),\(^9\).

To encourage the solidarity that is essential for social-distancing to be effective, the UK government bled the mantra ‘we are all in this together’, during daily televised briefings. However, it is clear that during this challenging time, NHS foundational values, such as Everyone Counts and Respect and Dignity, were beginning to be overlooked.

An outpour of creative responses to individual and collective hardships surfaced. Projects such as Rachel Gadsden’s Deluge (Gadsden, 2020) saw disabled and non-disabled artists collaborating, drawing inspiration from one another. Numerous creative works reached a worldwide audience, often without financial remuneration. Chris Martin and other pop stars streamed free concerts from their home (Savage, 2020). Participation from the general public was encouraged, and thus new

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\(^6\) The UK lockdown meant that the performing arts market saw a substantial downturn. The Music Venue Trust reported a 27% downturn in attendance across the UK. The Association of Independent Festivals said that ticket sales for its members were down 44% compared with the same point last year. Some estimates suggest the live music industry will lose as much as $5bn during the outbreak (Savage, 2020).

\(^7\) Disabled people were concerned, and rightly so, that the rights of disabled people (as set out in the Human Rights Act (1998), the Mental Capacity Act (2005), the Adults with Incapacity (Scotland) Act (2000), the Equality Act (2010) and the United Nations Convention on the Rights of Persons with Disabilities (2006) as well as in the Convention on the Rights of the Child (1989) were not upheld and they urged the NHS staff to be guided by these (Disability Rights UK, 2020).

\(^8\) www.nice.org.uk/guidance/ng159/chapter/Update-information

\(^9\) The International Disability Alliance (2020) also published key recommendations for disabled people and their treatment during the pandemic.
communities emerged, such as *The Sofa Singers*\(^\text{10}\); hundreds of people singing in chorus, using the online video conferencing platform Zoom\(^\text{11}\). Footage of music performances staged from homes and balconies went viral, germinating through popular hashtags such as #coronasongs, #quarantunes, #covidance, #pandemix, and #songsofcomfort. Whilst the altruistic acts of those in the performing arts sector is laudable, it is critical to draw attention to a deeper societal issue, that of the undervaluing of creative works, as there is a...

‘tendency to oversupply culture work as an antidote to crisis (let’s call it a creative generosity) is welcome insofar as it highlights the benefits of art and performance in times of distress and isolation. At the same time, this practice risks normalising the widespread idea that artists are performing a free service to which ‘consumers’ are entitled.’ (Tsioulakis and FitzGibbon, 2020)

As an emergency response to the pandemic, a new UK Disability Arts Alliance was launched under the #WeShallNotBeRemoved\(^\text{12}\) hashtag, to ensure a sustainable future for disability and inclusive arts in the UK, to...

‘amplify the voices of D/deaf, neurodivergent and disabled creative practitioners & disability arts organisations at a time of crisis for the arts and for disabled people.’ (UK Disability Arts Alliance, 2020)

Their *day of action* shared work by disabled visual artists, actors, directors, writers and dancers, while highlighting concerns that arose through the pandemic\(^\text{13}\). Artists stood at the forefront of a global, distributed effort of creative, cooperative generosity, fostering social cohesion in a time marked by disruption, distance, anxiety, and, sadly, death. The value of the performing arts and their necessity for a society in crisis seemed to be a positive outcome within an otherwise somewhat disruptive period.

Alongside the diverse voices of artists, a plethora of nascent software tools emerged, adopted by artists for network-based, collaborative musicking. Notable examples include Endless\(^\text{14}\), Jamkazam\(^\text{15}\), LiveJAM\(^\text{16}\), Jacktrip\(^\text{17}\), Jamulus\(^\text{18}\) and Audiomovers\(^\text{19}\). PwB began using new technologies during this time, too, developing a bespoke system for inclusive music performance (Lucas, Morgan, McCord, Leatham, 2020).

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\(^{10}\) [www.thesofasingers.com](http://www.thesofasingers.com)

\(^{11}\) [https://zoom.us/](https://zoom.us/)

\(^{12}\) [www.weshallnotberemoved.com](http://www.weshallnotberemoved.com)


\(^{14}\) [endlesss.fm](http://endlesss.fm)

\(^{15}\) [www.jamkazam.com](http://www.jamkazam.com)

\(^{16}\) [blog.smule.com/go-live USING-livejam-on-smule](http://blog.smule.com/go-live USING-livejam-on-smule)

\(^{17}\) [ccrma.stanford.edu/software/jacktrip](http://ccrma.stanford.edu/software/jacktrip)

\(^{18}\) [llcon.sourceforge.net](http://llcon.sourceforge.net)

\(^{19}\) [audiomovers.com](http://audiomovers.com)
Technologies, such as network infrastructures and music software, do not exist in a silo; they link intimately with human activities. As humans, we do not just use technologies, but we think with and through them, as Alva Noë had so poignantly stated (Noë, 2015: 25). Furthermore, these tools do not merely amplify what we can do, but they also teach us new things. For instance, at the outset of the COVID-19 pandemic, many people were learning new ways of ‘translating’ communal activities to video conferencing platforms. Indeed, how does one hold a birthday party, blow-out a candle, share a glass of wine, in the absence of tactile, tangible human interaction? Technologies act upon us, they influence and organise us, generating thoughts that we might not otherwise think, placing us on creative trajectories and distributed endeavours, possibly not previously envisaged.

As a result of the pandemic and adoption of new technologies, PwB reorganised its process of participatory design; it became distributed by necessity. The Distributed Design EU Network\(^\text{20}\) has already begun considering notions of distributed design. This network aims to reduce the ecological impact of production and consumption, leveraging global connectivity to move data, not goods. It is possible to distribute both design and fabrication, utilising local supply chains. The network argues that distributed design can provide consumers with more control over the design of the products they use, by allowing them a voice in the production process. Their approach of open and accessible design aligns with work carried out within PwB.

Despite longstanding activities in the area of network music/distributed performance and the emergent Distributed Design EU Network, it became clear that the idea of distributed participatory design was novel not just to PwB but more broadly speaking. Through distribution, the outcomes of PwBs activities changed; participation levels became affected; PwB realised different designs. Although we will never know of alternative realities, we can compare and reflect on our design efforts before and during the pandemic.

3. Participatory Design Before the Pandemic

In all design activities, PwB follows an agile design approach (Saadia Minhas, 2019). In such a design project, the key stages of an iterative cycle are likely to be similar to Design, Build and Test, as shown in Figure 1. Ancillary activities, such as planning and administration, often accompany these stages. This iterative, cyclical approach allows PwB to test design concepts quickly, using rapid-prototyping techniques, subsequently refining designs based on artist feedback. Technologies, no matter how rudimentary, are not static; they "both invite and incite refinement and improvement" (Noë, 2015: 26) and they not only allow us to solve problems, but they also frame new ones.

*Figure 1: Agile Design Cycle*

When considering inclusion, an effective ethos is to design *with*, rather than *for* disabled people. In their work, PwB adheres to James Charlton’s memorable slogan ‘Nothing About Us Without Us’ (1998), a motto stemming from the disability rights movement. PwB has Three Pillars of Inclusive

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\(^{20}\) distributeddesign.eu
Design: Accessibility, Usability and Value as detailed in Figure 2. In the design of bespoke, accessible music technology (AMT), PwB realises the three pillars through genuine and meaningful participation of disabled people in the design process, and those close to them.

Figure 2: PwB's Three Pillars of Inclusive Design

3.1 Accessibility
Accessibility falls under the umbrella of user experience. We can distil accessibility into categories such as physical, visual, and cognitive access. To date, PwB has primarily worked with physically-disabled artists, such as Eoin Fitzpatrick, a member of the Drake Music Project Northern Ireland (DMNI). Between 2018 - 2019, Eoin participated in the design of a physically accessible bespoke guitar, which came to be known as Instrument One, pictured in Figure 3. Eoin tested his instrument, leading to its realisation at DMNI premises in West Belfast; a wheelchair-accessible music studio, in late 2019.

Figure 3: Instrument One: A Bespoke, Accessible Digital Guitar

Through this process, PwB were able to disprove early assumptions of which control modalities would be physically accessible to Eoin. For instance, PwB assumed that a sip/puff switch would be an effective way for Eoin to select chords on his guitar. As Eoin drinks from a straw, sipping came naturally to him. However, it was challenging for Eoin to puff, without intermittently sipping. Together with Eoin, PwB decided that a general-purpose chin-operated access switch would be a more suitable interface element. The most straightforward way to determine whether or not a design is physically accessible is through in-person testing of prototype designs.

3.2 Usability
Usability, like accessibility, forms part of the overall user experience. While there is a degree of crossover between the two, usability distinctly focuses on qualities such as intuitiveness and user satisfaction (Usability.gov, 2020). If a device is frustrating to use, then it is less likely to be used, reducing its value. Returning to the example of Eoin and his musicking, when Eoin uses music technology, its use is facilitated in a variety of ways. For instance, during a DMNI workshop, Eoin's Music Tutor Daniel will set up music technology for Eoin to use; i.e. configuring settings, mounting equipment on Eoin's wheelchair. At home, Eoin's father Peter, a digital immigrant, is the facilitator. Therefore, in the design of Instrument One, PwB needed to consider usability from the perspective of facilitators and of Eoin.

User Experience (UX) Designers use wireframing tools, such as Axure RP or Framer, to create digital simulations of user interfaces. Testing these software-based prototypes with representative

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21 github.com/alexmlucas/i1
22 orin.com/access/sip_puff/
23 orin.com/access/orby/
24 www.axure.com
25 www.framer.com/
users is an effective way of identifying usability issues. It is a method best suited to the simulation of ancillary functions, loading a sound preset, for example, rather than demonstrating creative musical interaction (i.e. any form of interaction which results in the generation of sound for artistic purposes).

PwB simulated early versions of Instrument One’s user interface using Axure RP (Figure 4). Peter and Daniel tested the wireframes, with a member of PwB onlooking, setting tasks and asking questions. This stage of testing did, indeed, highlight usability issues. For example, Peter was unsure what the terms Global and Value meant, stressing assumptions made by PwB that these were universally understood terms. These descriptors were subsequently changed to Menu and Selection, respectively. Axure RP can quickly deploy wireframes to the web, making it feasible to conduct user experience tests remotely. However, there is a certain amount of convenience to be gained through in-person testing. When sharing the same physical space, a designer can look over the shoulder of a user with ease, watch the mouse cursor and observe their behaviour.

Figure 4: Instrument One: A Wireframe of an Early Interface Design.

3.3 Value

Value in this context primarily pertains to the benefits the technology brings to the creative endeavours of the artist. Artists value creative opportunities; by extension, the technology that unlocks such opportunities has value too. Designers must test the technology in a creative context, to assess and maximise creative value. Tools such as Axure RP fall short when it comes to the simulation of creative musical interaction. For this type of interaction, the designer must turn to other means, often software such as Pure Data\textsuperscript{26} or Cycling 74’s Max\textsuperscript{27}. PwB used a different selection of technologies when prototyping Instrument One, as detailed in Figure 5. The technologies used allowed for rapid prototyping of a variety of sensors and mapping strategies but required expert-knowledge to set up. It is not easy to envisage such an esoteric prototype being configured and used without members of PwB physically present. Significant modification is required to use this prototype in a remote evaluation session.

Figure 5: Instrument One: Musical Prototype

3.4 Levels of Participation

Harder et al., describe the depth in which levels of participation in the key stages of a project between two or more actors can occur (Harder, Burford, Hoover, 2013). Furthermore, levels of participation are mutable; they can change during a project. At its lowest level, participation is non-existent. For example, an expert might actively denigrate the ideas and perspective of a project benefactor. At its highest level, dichotomies such as designer/user become dissolved, ownership of the project is shared, collective decision making occurs.

\begin{footnotes}
\item[26] puredata.info
\item[27] cycling74.com
\end{footnotes}
Table 1 provides examples of Eoin, Peter and Daniel’s participation levels in the Instrument One project. Although ineffective when considering fluid degrees of participation, for conciseness, the authors will defer to the terms designer and users to refer to the primary researcher and Eoin, Peter and Daniel respectively.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Example Activities</th>
<th>Level of participation</th>
</tr>
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| Design | - The development of user stories and use cases.  
- Devising musical mapping strategies for control sensors | - The designer learns from the users through semi-structured interviews.  
- Users are given choices between mostly predefined elements. |
| Build | - Digital fabrication i.e. 3D printing.  
- Rudimentary software and electronics design. | - The designer was solely responsible for these activities. |
| Test | - Assess the physical accessibility of prototypes.  
- Assess ease-of-use through user-experience testing. | - The designers and users learn together by testing prototypes in-person.  
- Users are considered experts in the access barriers they face in making music.  
- The users suggest ideas for refinement. |
| Refine | - Refactor or fine-tune prototypes.  
- Discard ineffective mapping strategies. | - Whilst refinements are informed through user-participation in testing, they are made by the designer. |

Table 1: Levels of Participation in the Design of Instrument One.

Table 1 shows that Eoin, Peter and Daniel participated in some but not all stages of the agile design process. Inherently, a core goal of participatory design is participation itself. The involvement of those directly impacted helps to ensure the realisation of a suitable design. Full participation of all stakeholders in all project activities, from pivotal design decisions to medial tasks is laudable indeed. PwB found in their collaboration with Eoin, Peter and Daniel that this depth of participation was not possible and in some ways not necessary in meeting the Three Pillars of Inclusive Design. For instance, Eoin would not need to participate in building prototypes to meet user stories such as the one below.

‘As a composer and instrumentalist, I want to be able to record my instrument during a music workshop easily.’

PwB assumed a lead role in the Instrument One project, deciding when evaluation meetings would take place, which topics to cover and which technologies to explore. PwB strived to include Eoin, Peter and Danny in project activities as far as practicable. However, PwB made pragmatic
decisions, for instance, deciding not to invite Eoin to participate in prototyping activities such as software development. Due to the physical barriers, he experiences in accessing computers, Eoin is not computer literate. It would have increased the scope of the project to an untenable timescale to address these access barriers. In hindsight, creative-thinking could have facilitated Eoin's inclusion in these activities. Expert-novice pair-programming, using a *driver-navigator* approach (Dietrich, 2017) could be a viable way for Eoin to participate in future prototyping activities if he so wished. More broadly speaking, it is critical for academics involved in similar projects to be mindful of the control they may possess over the participation levels of project benefactors.

4. Distributed Participatory Design During the Pandemic

When the UK lockdown came into being, PwB were engaged in a second participatory design project with physically disabled DMNI artist Tim Leathem. PwB and Tim were collaborating on the design of *Instrument Two*, a bespoke, accessible drum machine, designed to augment Tim's rhythmic playing, pictured in *Figure 6*.

*Figure 6: Instrument 2: A Bespoke, Accessible Drum Machine*²⁸

Lockdown forced PwB to reorganise their approach, moving towards distributed, participatory design methods since in-person evaluation sessions were prohibited. PwB continued to interview Tim, but via video conferencing tools. Human interaction relies on a complex series of subtle social cues, which are filtered by digital communication technologies (Newport, 2020). For instance, a tone of voice is difficult, near impossible, to perceive in a text message, a change in facial expression might be lost or delayed in a video call. Would PwB miss critical social cues in Tim’s responses when conversing via digital means? An examination of the Instrument Two project, through the lens of the Three Pillars of Inclusive Design, helps appraise the changes made in the now distributed participatory design activities.

4.1 Accessibility

Tim has cerebral palsy, a broadly congenital condition which affects movement and coordination²⁹. Before lockdown, Tim had participated in several in-person, semi-structured interviews, to guide the access requirements of his bespoke instrument. These interviews lead to the creation of several *use cases*, some, such as the one below, highlighted the importance of physical accessibility...

‘*User interface controls are required to be appropriately sized, and spaced from one another to allow for easy targeting and operation.*’

Ideally, Tim would determine the appropriate size and spacing of controls through in-person testing of physical prototypes. PwB were therefore in a quandary during the lockdown as University and DMNI guidance forbade any person-to-person contact. PwB turned to paper-prototyping as a

²⁸ https://github.com/alexmlucas/i2
²⁹ www.nhs.uk/conditions/cerebral-palsy/
means of evaluating accessibility; a common low-fidelity, rapid-prototyping technique used for rendering an approximation of user experience. Tim printed a 1:1 scale representation of the user-interface at home with assistance from his family, allowing him to test the physical size and spacing of its controls.

Two-dimensional prototypes cannot represent the height of controls; an inherent limitation. The user interface of Instrument Two features two sliding potentiometers with raised DJ-style fader caps (i.e. a raised cap perpendicular to the interface panel). Through past research (Lucas, Ortiz, Schroeder, 2019) PwB was already aware that DJ-style fader caps were easier for Tim to target and operate than console-style (i.e. flat caps, featuring a groove for placing the finger, standard on mixing consoles). Conversely, it can be difficult for Tim to lift his hand over raised controls like DJ-style faders. If a fader cap is problematic, its position hindering access to other interface controls, this may only come to light at a later date.

4.2 Usability
A design goal shared by Tim and PwB was for Tim to access all features of Instrument Two, independently, reducing the need for facilitation. To this end, PwB tested the usability of Instrument Two from Tim’s perspective. PwB used Axure RP to create a wireframe facsimile of menu functionality. PwB deployed this wireframe as a web page, which Tim was then able to access on his iPad, using its touchscreen to interact with the simulation during remote evaluation sessions. As Tim also uses his iPad and its camera for video conferencing, PwB could not observe, while Tim tested the wireframe. PwB were mostly reliant on one of Tim’s carers to describe what Tim was doing and report on any issues encountered.

These evaluation sessions with Tim were significantly diluted, in comparison to in-person user experience testing with Peter and Danny. Furthermore, the wireframe web page generated by Axure RP has accessibility issues when used with a touchscreen, complicating usability evaluation. Tim tends to drag his finger across the screen after an initial touch. Axure RP renders wireframe interface elements as Scalable Vector Graphics (SVG). On iOS, the press and drag gesture is an interaction used to download images (including SVG files) from a web page to a device, resulting in wireframe interface elements not being actuated in some instances. Regardless of these challenges, PwB was able to identify potential beneficial improvements to the interface design. For example, as Tim has dyslexia, control functionality may be best described through the use of icons rather than text.

4.3 Value
PwB created a prototype of Instrument Two’s performative, rhythmic pattern-generating capabilities, using Pure Data and Ableton Live. This prototype helped Tim assess the creative value of Instrument Two. Tim was given a demonstration of the prototype during a video conferencing call; however, he has yet to interact with it directly. The prototype currently runs on a single computer, local to one PwB researcher. With some technical guidance from PwB and support from a carer, it would be possible for Tim to use a Pure Data patch to communicate with the prototype running on
the PwB researchers local computer, via networked OSC messages. Unfortunately, it will be challenging for PwB to recreate the embodied experience of performance-based musical instrument interaction, critical to evaluation, with the inherent latency of such a system, 10ms being the threshold at which the human ear will perceive a delay between action and sound (Wessel, Wright, 2002). Achieving such low latency is challenging, if not near impossible with current network technologies. Recently, Rebekah Wilson introduced the idea of individuals "becoming latency native" (2020), i.e. that over time, musicians and performers will become accustomed to networked audio latency. We are, of course, not often impeded by the inherent latency incurred by sound travelling through air. However, when working in a network environment, dependent on person-to-person real-time interaction, network latency is problematic.

During the lockdown, Tim has continued to participate in the design of his instrument. While we cannot easily say if Tim's level of participation would have differed had the lockdown not occurred, it is encouraging to note that Tim's level of participation has been similar to that of Eoin in the Instrument One project. Furthermore, there is one positive exception; Tim is currently actively involved in sound design tasks. Tim is selecting and grouping drum samples for the four drum kits that will feature on Instrument Two. This activity falls firmly into the Build stage of the Agile process, providing a depth of participation PwB had not previously achieved. Furthermore, despite initial concerns over loss of nuance when conversing via digital means, PwB and Tim have been able to improve the design iteratively, through discussion. However, one caveat remains; the lack of in-person testing has resulted in uncertainty over the design, which is highlighted by Tim's comments below.

'I've found designing during the lockdown okay. I miss being able to try things out in person and with the actual instrument. Video calls are better than nothing, but my input is basically an educated guess. I'm dying to get my hands on the instrument to see what I can do with it. Only then will we really know if the design is suitable for me to play or not.'

Indeed, Tim's concerns regarding the suitability of the instrument to his access requirements are well-founded. There will be physical constraints in the design. Physical constraints can be advantageous in design, guiding a user toward a particular and correct course of action, in-turn improving ease-of-use (Norman, 2013: 125). When designing a physically accessible device for a broad user group, adaptability is an essential attribute. Adaptability is an antithesis of constraint. Soundbeam (footnote) is an excellent example of adaptable AMT, the ultrasonic beam used to trigger musical material can be tailored by end-users to match a range of movement. Conversely, the adaptation of Tim's instrument is happening up front, during design, rather than during end-usage. The size, shape and position of controls on the finished instrument will be physically constrained, tailored to Tim. To finalise the design, Tim will need to complete his evaluation by interacting physically with the instrument, to validate the design as accessible, usable, and of value in his music-making.

5. Positive Outcomes
It is essential when collaborating with disabled people, for researchers to avoid a paternalistic perspective; viewing disabled people as in need of charity and support from others. Disabled people
are indeed disproportionately affected by the pandemic. While it cannot be assumed that one person’s experience of disability is similar to others, Tim is an example of a resilient disabled artist, continuing to create music, participating in design activities, maintaining his characteristic optimism. In some ways, Tim has benefited from the transition to remote, distributed ways of working. For example, with PwB and fellow Belfast-based DMNI artists, Tim composed and performed original piano music over a network. PwB submitted this recorded performance to the international New Interfaces for Musical Expression Conference NIME 2020 (Lucas et al. 2020). Originally planned to be hosted by Birmingham Conservatoire, the conference alternatively ran as an online, distributed event for the first time. Had the conference been in-person, the artists may not have been able to participate. PwB would need to secure travel and accommodation funding for the three artists and their carers. Wheelchair access barriers in the built environment, which includes transport and accommodation, would need to be considered. These challenges are not insurmountable but would require careful attention.

The primary PwB researcher, involved in the development of Instrument Two, is Alex Lucas. Originally from the south of England, Alex moved to Northern Ireland to join the Sonic Arts Research Centre (SARC), as a PhD candidate. Being physically separated from family and old friends during the pandemic has been difficult for Alex. In 2008 The New Economics Foundation produced a report on the Five Ways to Wellbeing (New Economics Foundation, 2020) - later reflected on in the context of COVID-19 social-distancing30. Based on extensive research, the document aims to prescribe key actions that improve well-being. These actions include Connect (with others), Be Active, Be Curious, Keep Learning, and Give. Alex has undoubtedly enjoyed remaining connected with Tim during the lockdown. Together they have remained active and curious about the design. Alex has continued to learn about Tim, the access barriers he faces and his musical goals. Alex derives a sense of satisfaction from the project, being able to give his expertise to the research group; his well-being has benefitted. In participatory design, all participants have the potential to be project benefactors.

6. Summary
This article began by examining ideas of distributed creativity, highlighting the nascent notion of Distributed Participatory Design. This category of design traverses other pre-existing forms of distributed creativity, for example, distributed listening and telematic performances. The authors gave a brief overview of the creative arts during the global pandemic of 2020. They argued that artists stood at the forefront of a global, distributed effort of creative, cooperative generosity that helped foster social cohesion in a time of distance and disruption. Disabled people faced discrimination in government guidance on the provision of medical care. The UK Disability Arts Alliance #WeShallNotBeRemoved initiative championed the voices of disabled artists in the UK, promoting their work while highlighting concerns of the pandemic.

The authors reflected on the work of PwB in accessibility and inclusion, how their participatory design activities were reorganised and distributed by necessity. The Three Pillars of Inclusive

30 https://neweconomics.org/2020/03/five-ways-to-wellbeing-at-a-time-of-social-distancing
Design (Accessibility, Usability and Value) provided a framework for the analysis of two participatory design projects, Instrument One and Instrument Two. Comparisons drawn between these two projects, reflected on levels of participation, before and during the pandemic. Despite the lack of in-person testing, Tim's participation levels during the pandemic were similar to Eoin's beforehand. Seemingly users such as Tim and Eoin are not the only beneficiaries of such participatory projects. Those traditionally filling the role of designer, benefit from the opportunity to connect with others, to feed their creative curiosity, to learn. Tim and Alex are creatives, on a shared endeavour and as such PwB has had a glimpse of dichotomies such as designer/user beginning to dissolve.

The global pandemic taught PwB about the subtleties of participatory design and helped generate new thoughts and discussions around inclusion in music. PwB gained specific insights into the relationships present in musicking as an organised activity. PwB questioned themselves, not only as individual organisms but as social networks of people, our relationships to one another, as artists, as listeners, and our approaches to how we design in a distributed scenario.

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