

Creating Time for LGBT+ Disabled Youth: Co-production Outside Chrononormativity

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journals.sagepub.com/home/sro**Harvey Humphrey** 

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Abstract

This article explores how ‘chrononormative’ constructions of time shape research and offers an approach to co-production and research involvement that draws on insights from trans, queer, and disability studies. The article presents early reflections on an NIHR School for Social Care-funded research study, approved prior to but developed under the context of the Covid-19 pandemic, investigating personal support, sexuality, and gender in young disabled adults’ lives. This project has been supported by a Participatory Advisory Group (PAG) of LGBT+ young disabled adults and we reflect on how engagement with the PAG has shaped our understanding of debates around time and involvement in co-production discourse. Our engagement with trans, queer, and disability theory allows us to think about the constraints on time that such involvement has pushed against as we have sought to account for the diverse needs of the body-minds of the PAG in pandemic times. We suggest that this may speak to opening up the diversity and accessibility of co-production across other research contexts and intend this piece to encourage these conversations. The article thus offers a critical exploration of themes of time, embodiment, and identity in the way in which co-production is enacted in funded research.

Keywords

chrononormativity, co-production, disability, involvement, participation, queer studies, social care, time, trans, young people

Introduction¹

This article explores normative constructions of time and its relationship to co-production. We use the concept of chrononormativity to engage with temporal orders in research, and how these ground expectations around pacing, ordering, trajectories, and the ‘right’

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time (Riach et al., 2014). Developed by disability, queer, and trans scholars, chrononormativity references the construction of time as linear and logical (Freeman, 2010). This has been attributed to the enclosure of people's realities in standardised 'clock time' and to heteronormative ideas of reproduction that organise futures (Kafer, 2013; Samuels, 2017; Samuels and Freeman, 2021). Our engagement with co-production stems from our observations on an NIHR School for Social Care-funded research project investigating personal support, sexuality, and gender in young disabled adults' lives. This research has a temporal ordering, established through research contracts and workloads and represented in research instruments and plans, such as Gantt charts, which reflects the way time is a 'resource' (Mason, 2021). Yet co-production can work against the grain of anticipated research time by demanding that work gets slowed down or managed flexibly. Drawing on experiences during the Covid-19 pandemic, we explore tensions with normative temporal expectations as we have worked with a group of young LGBT+ disabled adults.

We approach co-production through the lens of queer, trans, and crip time to better account for the diverse needs of the body-minds of our co-production group, which they share with the project's prospective participants.² We use body-mind as a feminist disability studies term to account for a diverse range of disabilities and experiences including physical, sensory, mental ill health, neurodiversity, and pain (Price, 2015). Our aim is not to offer guidelines or a definitive approach to the involvement of young disabled adults who are LGBT+ in pandemic times, or any other. Instead, this article reflects upon the possibilities of temporalities as research methods alongside the unique challenges of the Covid-19 pandemic in which we have co-produced research. This has presented not only research challenges, but personal challenges for LGBT+ and disabled young people, such as risks to health and body, restrictions in access to personal support, and diminished possibilities to make choices and take control of one's life in lockdown (Gonzales et al., 2020; Konnoth, 2021; Rotarou et al., 2021; Shakespeare et al., 2021). These have invariably impacted on possibilities for participation among these groups. The challenges and our continual reflection on the ways we work together cause us to ask broader questions about access and involvement in research.³ These questions consider who research involves and is accessible to, including participants, co-production group members, and researchers. We hope our reflections on these research experiences speak to others engaging with questions of accessible and inclusive research practice and we intend this piece to contribute to ongoing discussions in these areas.

The specific structure of this article embraces what Freeman (2019) calls 'chronocatachresis', a deliberate disrupting and reimagining of time by locating different narratives in different spaces on the page. Inspired by Annemarie Mol's (2002) *The Body Multiple*, we offer more concrete examples of the organisation of the project in the footnotes, to distinguish it from the more conceptual narrative in the body of the text. We ask the reader to follow these two different narratives, and to explore their connections and divergences, alongside or outside of the temporal order of the article.

The discourse of participation

Participatory involvement is a growing discourse in health and social research. Promoted by funding bodies such as the UK's National Institute for Health Research,

co-production advocates for researchers, practitioners, and members of publics affected by research to work together on research studies (NIHR, 2021). This discourse has emerged with the push for greater democratisation in science (Mason, 2021; Oliver et al., 2019), an ethos of user empowerment in health and social care (Langley et al., 2018), the impact agenda in academic research (Greenhalgh et al., 2016), and the desire for meaningful research collaboration among affected communities – as in the disability movement slogan ‘nothing about us without us’ (Charlton, 2000; Facer and Enright, 2016). A key component is power sharing. Co-production calls for power to be shifted from professionals to those ‘traditionally on the receiving end of professional expertise’ (Williams et al., 2020). The objective is to improve the design and delivery of research *for* affected communities by ensuring those with lived experience shape research agendas.

Co-production has seen interest in approaches to collaboration grow, and it is often observed that there is no single model of co-production. Rather, co-production reflects the needs and agreements of diverse groups doing things together. It entails complexity in planning, designing, and progressing research (Oliver et al., 2019). As Redman et al. (2021) argue, because co-produced research can involve conflict, it also calls for trust, co-learning, and co-operation. It is context-dependent, meaning that what works one time under specific circumstances may not apply in a different setting or with a different group.⁴ Additional resources may also be required to aid participation. Developing and nurturing collaborative partnerships and building trust means that genuine collaboration takes longer than research is typically funded to take (Beran et al., 2021). For example, Mason (2021: 15) argues for the value of ‘staying’ as ethical practice in participatory research that enables ‘deeper affective ties and enhanced opportunities for reciprocity, rooted in purposeful investments beyond research’. Time also matters when groups come to research with specific time-related needs, such as commitments and time restrictions owing to care, health, or disability, and embodiments that make some temporal patterns of involvement impossible or undesirable (Liddiard et al., 2019).

Research time matters because it is about power. As Wendell (1996) argues, temporal orders that do not suit disabled people’s body-mind requirements can be a barrier to participation. Liddiard et al. (2019: 163) describe how they used ‘crip time’ to frame ‘alternative orientations in and to time’ in their co-produced research involving young disabled women. This included contesting expectations that collaboration happens in concentrated times fixed in research calendars, working around when people were not available owing to health or social care needs, and changing the pacing of research interactions to respond to experiences of fatigue, pain, or fluctuations in attention. An emphasis on being flexible with time has also been noted in research involving young people, who may not organise their lives along conventional work hours, or whose lives alter when they experience changes in their health, housing, work, or education situations, and so may be selective in research involvement as it stretches over the life of a project (Brady et al., 2018). Brady (2020: 249) argues that with young people ‘one size or form of participation does not fit all’. She advises thinking carefully about how young people can make choices around how participation can work for them in their contexts which may shift over time requiring opportunities for varying levels of involvement and inclusion.

Thinking against ‘normal’ time: crip, queer, and trans interventions

Our approach to co-production in the present context involves thinking through the importance of space and time to engagement with research and questioning the dominance of chrononormativity.⁵ Freeman (2007, 2010) defines chrononormativity as constructions of time according to notions of family and productivity typically marked by linear narratives of birth, childhood, adolescence, adulthood, reproduction, and death as ‘normal’. Queer, trans, and disability temporalities offer disruptions to these normative conceptualisations of time, highlighting ways time can feel stretched, or how imagined futures may play out in the present moment as a practice of imagining another life. For instance, Halberstam (2005) discusses extensions to queer adolescence outside of normative expectations constructing a queer temporality. Muñoz (2009) offers considerations of queer futures lived in the present to create queer possibilities for living. Similarly, trans temporalities have become associated with lives existing in periods of waiting and anticipation as well as non-linearities of co-existing pasts, presents, and futures (Amin, 2014; Malatino, 2019; Pearce, 2018a, 2018b; Simpkins, 2017). Trans temporalities construct possibilities of trans futures and trans bodies that could be – a temporality of possibility that exists in a long drawn-out now of waiting for that imagined future to be realised. The pandemic has further stretched these experiences of queer and trans time for some LGBT+ people less able to live their authentic lives in current contexts.

We also draw inspiration from Alison Kafer’s (2013) conceptualisations of crip time that reveal a need for more time for disabled people to complete a task or navigate encounters of compulsory able-bodiedness. Kafer’s work on crip time develops this idea further to offer:

reorientation to time . . . It is this notion of *flexibility* (not just ‘extra’ time) that matters. Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of ‘how long things take’ are based on very particular minds and bodies. . . . Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds. (Kafer, 2013: 27)

Our approach to co-production has embraced this flexibility in relation to time attempting to account for the diverse temporal needs of our co-production group and anticipating the temporal flexibilities that may be required for their participation.⁶ Brought together in the context of co-produced research, these crip temporalities highlight a way to co-produce that offers not only the ‘more time’ suggested by Redman et al. (2021) and Beran et al. (2021), but a different approach to time that offers a more flexible approach to inclusion of diverse body-minds.

We continue to develop our own approach to co-production by thinking through possibilities of involvement and flexibilities for engagement outside of chrononormativity. We make use of a form of trans and crip time that stretches the present moment of research at a time when it feels like once everyday activities are on hold. In co-producing research with LGBT+ young disabled adults, these trans and crip temporalities provide a methodological approach for inclusion and reimagining time in research and

researching body-minds in time and space.⁷ These also offer time and space for thinking through power relationships within research and ways in which time can also be a powerful ableist, capitalist, heteronormative structure (Glennie and Thrift, 2012; Halberstam, 2005; Kafer, 2013). Co-production research with disabled people has developed an understanding of accessibility that focuses on ‘more time’ to account for ways in which some disabled body-minds may engage with research practices. This idea of building more time into co-produced research with disabled young people is found in Olsen and Carter’s (2016) research with disabled people. Drawing on Liddiard et al.’s (2019) work on co-production with disabled young women and the possibilities of ‘more time’ offered to co-researchers to make participation accessible, including through online research spaces, we develop possibilities of flexible time (Brady et al., 2018) and grip temporality that allows for the development of the research to exist across multiple times and be experienced differently according to the different temporality requirements of our Participatory Advisory Group (PAG) (Kafer, 2003).⁸

Restraints on research time

This flexible, creative, and temporal approach does not come without limitations. Virtual space is not necessarily safe or accessible (Seymour, 2001). There is nothing inherently accessible about research that takes place online. It is, for example, much harder to know if a space shifts and becomes less accessible for a participant (or a researcher) than research conducted in the same in-person space at the same time (Humphrey et al., 2020). These are not yet complexities we have solutions for.

There are also limitations of institutional requirements and ethics processes. Work on slow scholarship (Mountz et al., 2015) and critiques of neoliberal temporal requirements of universities have highlighted those with the most power can afford to take the most time and slow research down (Breeze et al., 2019; Price, 2021; Samuels and Freeman, 2021). Funding bodies and higher education institutions’ expectations of research do not necessarily account for shifts in time, or embrace temporal flexibility, but instead seek to quantify and constrain time as a usable resource (Mason, 2021). There are pressures to submit and complete research, to work as if nothing had changed. Institutional and funded expectations compel us to stick to pre-pandemic timelines, and this can create challenges for researchers who may need to manage the contradictions of different temporal expectations. But the push to co-production described above, and advocated for by these organisations, including universities, may mean researchers feel more able to speak back, advocating for their co-production groups by maintaining a dialogue and working collaboratively with research sponsors to find ways to make time, such as working out potential extensions, as we have sought to do with this project as we grapple with the longer-term consequences of the pandemic. *It is a radical act* to embed that slowing down and taking time with research and responses across the project not just for those who may request extra time which would place the burden on them to ask for it rather than it to be already an important part of what we are asking from them. *It is a radical act* to make room for participants who require more time, those who cannot participate quickly, in any context.

This article has taken a moment to consider co-production and the importance of temporality as a methodological approach to this work. We hope this disjointed split narrative has given time and space for reflection on your own practices. This article raises more questions and complexities than it answers. We seek to contribute to the ongoing conversations on co-production, accessible research practice, and time and place of research. We look forward to future responses and conversations in other times and spaces on these important topics.

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Notes

1. READ ME! We invite readers to read the footnotes before, after, or alongside the main body of the article as they prefer. The footnotes deliberately ‘qrip’ queer/crip time and the flow of the article offering moments for disruption and reflection as readers engage with this work. We are inspired by Kafer’s (2021) use of endnotes to mark crip time and ask readers to find time for this.
2. This article discusses a study on personal support, sexuality, and gender in young disabled adults’ lives. At the outset, we recruited a diverse Participatory Advisory Group (PAG) of young disabled adults who are LGBT+ to co-construct and design the project. Undertaking co-production work with this diverse group during the Covid-19 pandemic has required us to think differently about space and time for this co-production to be accessible to these young adults and to include their diverse identities and body-minds.
3. As we have sought to construct space for the PAG, we have endeavoured to develop an approach to involvement that attempts to centre flexibility of time in our research. Offering a temporality as research method centres on two key questions we continue to ask ourselves: ‘What does it mean to centre the flexibility of time for a research project designed with and working for LGBT+ young disabled adults?’ ‘What does it mean to deliberately (or otherwise) slow processes down for research?’
4. Our interactions with the PAG have highlighted some of the tensions inherent in co-production and research collaboration. Who gets to decide on what, who writes what, and what the

research is or should be about. In the time it has taken to publish our reflections in this short article, we have moved onto thinking about outputs and training to be co-produced from this research project with the PAG. There are a range of considerations as we develop these outputs including ethics, power imbalances, co-authorship, and audience reflecting Bozeman et al.'s (2013) literature review of collaborative research.

5. The accessible form of co-production enacted in this project asks where and when research participation takes place. We focus on virtual spaces of engagement, and on giving time, such as giving the PAG materials to work with at a time that works for them, rather than meetings at set times. This questions the dominance of in-person co-production work in non-pandemic times.
6. The PAG communicate entirely online, seven via WhatsApp chat, with resources (potential topic guides, documents on data analysis methods) hosted in a shared digital folder. No one needs to be in a particular in-person space, or are required to read/respond to messages at a set time. This system has been designed because of both the pandemic and the communication needs and preferences of the PAG. This also speaks to the flexibility of time in mobile phone communication (Bittman et al., 2009). The virtual space and messages in suspended time account for diverse communication needs. Some need time to read conversations closely, and some find text-based communication less overwhelming or easier to follow. In these scenarios, words and voices are less likely to be missed: chats are available for anyone to read and respond to in their own time creating multiple temporal threads. Concurrent one-to-one chats with the researcher also allows some individuals to check in about particular comments or ideas further splitting the temporal and spatial possibilities of communication in this practice. One group member prefers a solo video call. The WhatsApp chats are summarised for them and their thoughts are relayed to the rest of the group adding greater flexibility to these conversations in time and space.
7. This is different to the anticipated process with people meeting in-person at one time all together. The members of the PAG we have may not have engaged with something set up like that because it does not account for the way they need research time to work for them or their communication or spatial requirements. Whereas this system allows everyone time to think in a space which suits them. There is no system to request more time or adjustments to a space because normative notions of time no longer apply and expectations of in-person space are expanded in virtual settings. This does not just work for the PAG. One of us is a disabled researcher with communication needs and flexible working requirements. These ways of rethinking temporality in research accounts for this body while retaining choices about being 'out' about disabilities and the complex power dynamics encountered in sharing such information.
8. This flexibility of space and time also translates to the flexibility of possibilities of creative methods in data collection. Suggestions of ways to include more flexible approaches of collecting data on potentially sensitive topics speak to decisions and designs of the PAG thinking through how they might have participated. These considerations of creative options were also a focus of the PAG's self-reflection on their membership. This creative approach aims to include those voices that are currently absent from the PAG membership. Who is not in the research yet? How do we make it accessible for their participation to be possible?

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