

What We Talk About When We Talk About Cloning: A Literature and Bioethics Perspective on Genetic Privacy, Consent and the Family

Paul Hamann-Rose

The concept of genetic privacy raises acute challenges in the twenty-first-century privacy landscape. Emerging from the twin revolutions in personal genetic testing and big data, genetic privacy presents a new and pressing bioethical problem. Today, personal genetic data are no longer being generated solely within clinical environments but also by myriad private companies like 23andMe or AncestryDNA. In the wake of this digital transformation of how personal information is produced and managed, definitions of privacy have shifted from the traditional formulation of the “right to be let alone” (Warren and Brandeis 193) towards “privacy as a personal right to control the use of one’s data” (Schwartz 820; see also Igo). Concerns over how to protect the increasing volumes of sensitive genetic information have sparked heated discussions both in the media and in specialized bioethics forums. Frequently highlighted privacy harms linked to the proliferation of genetic information include discrimination and psychological distress, breaches of confidentiality as well as diminished control and autonomy (Clayton et al.). Among these risks, a core worry is attached to the status of consent in the processing of an individual’s genetic data, especially with regard to their varied and possibly unexpected downstream uses (Clayton et al. 8-9). Because families in most cases share considerable genomic ties, the question of individual consent is further implicated in larger familial dynamics that entail additional privacy risks. My central argument in this article is that a uniquely helpful perspective on the legal, ethical and political uncertainties surrounding the complex of genetic privacy, consent and the family can be gleaned from literary fictions about cloning.

In recent years, a growing number of bioethics scholars have recognized the potential of fiction and film for bioethical research (Chan). In addition, bioethical concerns have increasingly driven investigations in literary studies (see, for instance, Gill; Garland-Thomson; or Eatough). The transdisciplinary promise of a joint bioethics and humanities framework lies in the critical and emotive vantage point that works of fiction afford on entangled issues like genetic privacy. Combining methods of literary analysis with crucial insights from both qualitative and quantitative bioethics research, my aim in this paper is to shed light on one of the most complex and hitherto neglected cultural negotiations of genetic privacy as well as to demonstrate the particular critical contribution of a literature and bioethics perspective. This transdisciplinary outlook gives rise to new readings of established literary fictions and positions literary analysis as a valuable resource in the bioethical toolkit, with significant implications not just for more abstract bioethical endeavours but also for concrete empirical bioethics.

While few literary texts explicitly investigate the privacy risks around genetic data, cloning narratives in fact constitute a substantive body of works that have been addressing the same anxieties as those evoked by genetic privacy since before the topic assumed centre stage in bioethical and public policy debates. Cloning narratives have been produced across a panoply of fictional media, including film, television, comics, video games, and other genres, but I concentrate on cloning narratives in novels in order to explore the aesthetically distinctive response of literary fiction to this key bioethical issue.

The novel form boasts a rich history of engaging evolving notions and realities of the private. It is thus ideally placed to examine critically the privacy challenges arising from new and emerging biotechnologies. In Jürgen Habermas's canonical argument about the emergence of the public sphere during the eighteenth century, the novel played a crucial role in consolidating the privacy of the intimate bourgeois family around individual practices of reading and self-reflexion. This then enabled – predominantly male – private individuals to come together as a public (Habermas 51; see also Hamann 65). From the beginning of modern conceptions of privacy, public and private socialities and politico-economic conditions have been interdependent and the novel a central medium in their negotiation.

The rise of widely available genetic testing products, as well as reproductive technologies such as in-vitro-fertilization and pre-implantation genetic diagnostics, have radically geneticized some of the most fundamental and most intimate aspects of private family relations. The genome has been morphed, as Lara Choksey puts it, into a "technology of post-industrial domesticity" and in its wake has changed "the terms and possibilities of the bourgeois private sphere even as it eradicated the [liberal humanist] subjects it targeted" by turning them into sets of data points (Choksey 84). These genetic transformations of the private sphere tie back to public forms of technocapitalism, which they thereby sustain. Because genetic testing is often accompanied by the large-scale collection of genetic and related physiological data, by both state and corporate actors, private intimacy is also made public to the extent that these data are publicly available or easily identifiable by interested parties. This poses challenges to the very notion of intimacy as a strong affective bond usually characterized by being inaccessible to outsiders, as well as its constitutive function for the traditional private sphere of the family. Because intimacy depends on privacy (for this see also DeCew) and families are characterized by intimacy, both intimacy and family relations will provide crucial and productive sites through which to examine the evolution of privacy under the pressures of genetic technologies and databases.

My focus is on cloning fictions written predominantly in a realist literary mode. In contrast to other genres, like science fiction, horror, or melodrama, the realist genre constitutes a comparatively small portion of all fictional treatments of genetics in general and of cloning in particular, as our research group's database of films and television series about genetics has powerfully put in evidence.¹ All cloning narratives at least present some elements of science fiction, if only on the basis that full human cloning remains hypothetical and is largely decried as both unethical and illegal (Ayala 8885). Science fiction was also the very first genre to take up the subject of cloning (Roxburgh and Clayton). Yet, the combination of the scientific and sociological imagination of science fiction with the psychological and affective concerns of literary realism often produce the most insightful reflections on the human meanings of social and technological change.

Cloning narratives in realistic novels are hardly ever actually about cloning (Marcus 406). Often the motif of cloning functions entirely as allegory or as a particularly incisive vehicle through which to interrogate other real or imagined biotechnologies. Instead of telling us anything about cloning proper, the cloning narratives I discuss contribute a privileged perspective on genetic privacy concerns. The figure of the clone begins its socio-political life with a fundamental lack of control over personal genetic information. Standing in for larger cultural concerns about biotechnology and agency, fictional clones then strive to regain as much privacy as possible, revealing in the process genetic privacy's implications for the individual, the family, their forms of intimacy as well as their surrounding social institutions.

Genetic Privacy and Consent in Family Settings

From the moment of conception, the genetic privacy of clones is compromised because the very method used to conceive them will have required their DNA to be extracted, most probably sequenced, and possibly stored for future use. Additionally, their genetic material has been passed down unilaterally from one source, rather than two parents, amplifying the already complicated relations defining control over shared genetic information in traditional family settings. The inability of clones to give or withhold consent regarding the discovery of their genetic information crystallizes their disadvantaged position and, as will be shown, is a core concern in novels about cloning. Of course, nobody has a say in the way they are born. However, the clone's circumstances are sufficiently different from traditional modes of conception to draw attention to and shed light on cultural anxieties about individual control of private information, including consent, as well as on the consequences of a growing culture of choice surrounding reproductive technologies.

While cloning is a very specific mode of reproduction, its consequences as an expression of reproductive choice and genetic manipulation are generalizable and resonate with larger debates on changing cultures of reproduction. Fictional depictions of clones struggling to reassert control over sensitive data, often, as my analysis will show, diminishing their ability to form and sustain intimate relationships, suggest the potential social and ethical costs of certain methods of reproduction. The clone's initial inability to consent translates, as he or she grows older, into acute questions of individual and familial power relations and thus preconditions the clone's future ability to consent in a more dramatic fashion than traditionally conceived children. It is precisely because of this complete initial absence of informational control that the clone offers such a powerful subject for a bioethical investigation of an impaired genetic privacy and the need for consent to keep information private.

In bioethical discourse, the concept of consent figures primarily as the notion of informed consent. Informed consent is a core value in today's clinical practice and "is premised on the disclosure of appropriate information to a competent patient who is permitted to make a voluntary choice" (Appelbaum 1834). Truly informed consent entails the ideal of providing the patient with the maximum of autonomy as their individual as well as clinical contexts allow. Recent efforts to complement consent with increased forms of shared decision-making are evidence of the high status enjoyed by this ideal (see, for instance, Elwyn et al. 2). When it comes to genetic privacy, the ability to give consent translates into a person's self-directed capacity to influence how their genetic information is used and by whom. In their "systematic literature review of individuals' perspectives on privacy and genetic information in the United States", Ellen W. Clayton et al. show that impaired consent is a chief yet understudied risk associated with genetic privacy (3, 7). In state-funded research, participants are now in most cases required to give consent to broad data sharing of their genetic information, raising concerns about whether participants in this way relinquish control over their data to an unacceptable extent (Clayton et al. 2). This is a significant issue for the viability of genomic research projects because if subjects should begin to lose confidence in the protection of their privacy, they might choose to withhold their data, stifling research (Gutmann 1032).

A primary point of contestation in this context is whether research participants should be required to re-consent to the use of their information beyond the original research setting, especially if they could be re-identified from their genomic data, or if children's re-consent should be required when they come of age (Clayton et al. 3, 8;

Gurwitz 1033). A related question is whether individuals need to give consent when close relatives demand access to test results potentially pertinent to their own health (Laurie 120-21; Clayton et al. 15). These concerns over possible downstream uses and disclosures of genetic data apply also to non-clinical contexts and pose a hot button issue particularly when information might be disclosed to insurance companies or employers (Clayton et al. 8), or used by firms like 23andMe for commercial pharmaceutical purposes (Ducharme). In all these scenarios, informed consent is associated with individual control over personal genetic data and thus emerges as a precondition for privacy.

How the issue of consent relates to matters of family can already be seen in the case of close genetic relatives asking for access to an individual's test results. Because all relatives share a proportion of genomic traits, individual consent regarding genetic data almost invariably affects other family members too. The adequacy of such consent is in question since it might entail impinging on the privacy of biological relatives. This conflicted site of genetic privacy has received major media attention in a law enforcement context. In 2018, police in California identified the so-called 'Golden State Killer' using the personal genomics service GEDmatch. GEDmatch offered an open-access platform for familial searches to look for genetic relatives based on the genetic data volunteered by its users. What is new about police turning to this service for their investigation is their use of a non-forensic database to find a genetic match for DNA collected at a crime scene (Ram et al. 1078). Through the service, police found a relative of the alleged killer whom they were then able to identify using additional demographic data (Erlich et al. 690). While the case proved a major investigative success, it brought to the fore the potential privacy harms involved in this form of criminal investigation. This case highlights potential violations of a constitutional right to privacy, a complex issue that remains unresolved even in light of recent decisions by the US Supreme Court (see Ram et al. 1078-79; Ram). As Natalie Ram et al. point out: "Suspects identified through familial searches cannot be said to have voluntarily shared their genetic profile in a database of known individuals, even if a genetic relative has." (Ram et al. 1079) What is at stake in this scenario, however, is not only a legal but also an ethical matter. There is currently great uncertainty about the potential impacts, both emotional and otherwise, on family members identified through genetic info-banks without their consent – particularly in the always distressing context of a criminal investigation. The urgency of this threat to individual privacy is powerfully underlined by recent studies suggesting that in the near future, though in conjunction with additional demographic markers, "nearly any U.S. individual of European descent" could be identified through distant relatives on genetic genealogy sites like GEDMatch (Erlich et al. 690).

Privacy risks not only arise when previously unknown distant relatives are genetically linked to each other. Genetic privacy can similarly become a concern within nuclear families. Conflicted control over genetic information is highlighted in families created through assisted reproduction. Emily Rauscher and Mark Fine identified several risks that parents worried about when faced with the question of informing their children or family outsiders of their use of assisted reproduction, "such as relationship deterioration, social stigma, loss of face, and emotional hurt" (Rauscher and Fine 223). Loss or deterioration of intimacy in family or other close relations is also one of the core consequences of impaired genetic privacy highlighted by the cloning fictions discussed below. In Rauscher and Fine's study, depending on the individual case, it was either the parents' or the child's privacy that was considered at risk from disclosing information about the child's conception. The central dilemma here remains contested among bioethicists: "debates in the literature on families conceived through ART

[assisted reproduction technology] have still not reached consensus on the issue of who should own and control information about a child's genetic origins, nor is it likely that they will anytime soon" (Rauscher and Fine 227). In their recent study of relatedness networks between siblings linked via a sperm donor, Rosanna Hertz and Margaret Nelson remark that increasingly donor-conceived children are being given control over whether they want to disclose their genetic origins in order to contact either the donor or potential donor siblings. They state that "[w]ithin both the world of donor conception and the world of adoption a new interest in openness prevails" and that in "both worlds choice is crucial" (Hertz and Nelson 10). In this context, control over genetic information emerges as a significant value in family constellations. If this power is withheld, other studies suggest – and narratives about cloning show – individuals may suffer distress and identity conflicts with detrimental effects on the family and their larger social networks (see Rauscher and Fine 23).

Genetic privacy is predicated on people's control over their data and violations of that privacy can affect their intimate and inter-familial relations. Little is known, however, about the effects of the new privacy harms on individuals and their family settings posed by genealogy sites and current genetic testing. I propose to turn to fiction for insights.

Approaching Genetic Privacy Through Cloning Narratives

In Fay Weldon's 1989 novel *The Cloning of Joanna May*, sixty-year-old Joanna May learns that thirty years ago her ex-husband cloned her without her knowledge. She is explicit about this: "I neither knowingly nor willingly consented to anything at all" (Weldon 197). Confronted with what she perceives are four younger versions of herself, Joanna is furious and feels that along with her genetic material something fundamental about her identity has been taken away – throughout the narration she contemplates who really is referenced by her use of the pronoun "I". Her strong sense of relatedness to the clones further underlines the significance of DNA as an identifier of kinship as well as identity in the novel. The text is only superficially concerned with cloning, however. Instead, as critics have previously noted, the novel uses the figure of the clone to interrogate the respective impacts of genes and environment on an individual's development and behaviour – a classical theme in cloning narratives – as well as to problematize woman's reproductive rights in a patriarchal society (see Marcus 406; Ferreira *passim*; Hamner 60). Weldon's work also exemplifies how cloning fictions frequently investigate the implications of genetic privacy and its impact on individuals and their intimate family relations, something scholars have so far neglected to observe.

Questions of control over personal genetic information are at the core of *The Cloning of Joanna May*. It is noteworthy that given its publication in 1989, its engagement with the issue significantly prefigures the major increase in bioethical interest in the subject around the turn of the millennium in the wake of the massive genetic databanks inaugurated by the Human Genome Project (Rose and Rose 2). This showcases the genre's sensitivity to bioethical concerns even before they appear on the discipline's radar. Pamela Sargent's *Cloned Lives* from 1976 is yet an earlier example of how representations of cloning contemplated new biotechnology's impact on thinking about identity and the family (Ferreira 151; Hamner 72-76). The salient point, though, is not that fiction might have articulated these concerns first but that it offers a rich corpus of texts contributing critical voices to the public debate on genetic privacy.

In the socio-historical context of Weldon's novel in particular, public debates about science, especially about new genetic technologies like genetic engineering and genetically modified crops, arose from a mounting distrust of science. Besides genetics,

it was the growing fears of radioactive fallout, explicitly addressed in the novel through Joanna's husband's running of a nuclear power plant, that led to concerted efforts within the science and science policy community to include members of the public in the decision-making process around such technologies (Rose and Rose 18). As Hilary Rose and Steven Rose point out, the inclusion of such non-expert advisors continued through the 1990s into the 2000s, for instance by the Human Genetics Commission in the UK. An increasing view of the mass-gathering of DNA as a form of surveillance has been a steady contributing factor to the public's unease about genetic science (18-21). However, as genetic data mining became ever more profitable, public inclusion policies have recently been overturned and the non-expert advisory committees largely dismantled. At the same time, genetic privacy emerged as a concept imbued with the value of protecting genetic data from corporate – and state – exploitation. This not only illuminates a new peak in the accelerating coupling of scientific and financial interests, which have become more and more distinct from the interests of the public, consisting of private individuals and families, but also highlights the need to find new forms of bringing cultural attitudes towards the new genetic technologies back into the fold. Literary negotiations like Weldon's of pressing issues like genetic privacy offer just such a mode of making available culturally and socially situated meanings and concerns attached to emerging biotechnologies.

Fay Weldon's cloning narrative provides a perspective on privacy harms around genetic data because its treatment of cloning evokes anxieties common to both cloning and privacy debates. For the most part, clones in fiction imaginatively evoke a set of anxieties that transcends the immediate context of cloning. In this way, the figure of the clone illustrates a characteristic of genetic fictions more generally, in which the treatments of genetic technologies are frequently expressive of underlying anxieties about post-war political power transformations and the rise of global corporate capitalism. The informational paradigm at the heart of genetic science further contributes to the continuing relevance of twentieth-century genetic fictions to twenty-first-century concerns about the joint revolutions in genomics and big data.

Cloning narratives regularly link topics like identity and family to questions of control over personal genetic data and consent. As a result, representations of cloning negotiate concerns relevant to current debates about genetic privacy. As early as 1982, Ruth Chadwick reflected that it "might be argued that cloning would violate a right to privacy. . . . The argument would be that cloning constitutes a transgression of the right, because the child's genetic make-up is known and foretold" (Chadwick 205). Chadwick also reminds us that the child "would not exist if he were not cloned" so that the "right could carry force only after he was born, and could then generate conclusions about access to information about his genotype, as it might do in the case of anyone else's genetic make-up" (Chadwick 205). Cloning fictions are in fact about "the case of anyone else's genetic make-up" – and productively so – in the sense that they use the figure of the clone to comment on larger social trends and concerns about genetics, power and society.

Besides the privacy harm manifest in the clone's lack of control over his or her genetic information, the issue of consent is another factor at play in Chadwick's scenario. Consent can either be in question for the donor whose genome is duplicated or for the child conceived in this way. Most fictional depictions of cloning someone without their consent present this as "absolutely reprehensible" (Marcus 408). Yet even if consent is given by a parent or donor, the cloned child inevitably has not consented to the procedure. Lori B. Andrews and Nanette Elster note that "[e]ven in cases where the donor waives privacy rights and releases private genetic information, the privacy

rights of the clone are necessarily implicated due to the fact that the clone possesses the same nucleic genetic code" (Andrews and Elster, cited in Laurie 116). A cloned child invariably struggles with having been denied the ability to consent to a third party's use of their genetic data; hence the four clones' outrage in *The Cloning of Joanna May*. Considered more figuratively, the clone thus becomes representative of an underlying social unease about external access to intimate information perceived as private.

An inability to control genetic information, as we have seen in Rauscher and Fine's study, can prove detrimental to a person's sense of identity and family belonging. In family settings, making use of someone's genetic information without their approval "engenders not only legal problems (a severe violation of one's rights over his or her body) but also undermines the foundations of familial relationship: trust, sincerity, and cooperation are replaced by deception and secrecy" (Marcus 411). Familial relations and the possibility for intimacy are interlinked with family members' abilities to protect their privacy and share information on their own terms.

However, fictions also depict ways to combat privacy harms. In *The Cloning of Joanna May*, the narrative follows Joanna and the clones in their attempt to build a sense of familial relationship despite the damage done to their individual identities. At first, one of the clones vents her anger, saying the revelations had turned them into "orphans"; and her suggestion that they "should sue" clearly indicates that she feels wronged by the third-party intervention into her private life (Weldon 233). But as Joanna and the clones regain control over their genomic data and begin to form a bond, a kind of intimate relationship emerges which they had been previously denied. Joanna comes to refer to the clones – if in complicated terms – as "her sisters, her children, her family" (Weldon 197). Beyond the literal mantle of cloning, the story suggests how an impaired genetic privacy can result in the traumatic loss of both family and identity. But it also suggests how a regained sense of genetic privacy marked by control and consent can produce new kinship relations and alternative forms of intimacy and belonging.

The Cloning of Joanna May, an early realist novel about cloning, already evinces the potential of the cloning narratives discussed below to contribute to bioethical conversations about the risks involved in the explosive increase in personal genetic data. The affordances of literary texts in this respect are manifold. They draw attention to the bioethical urgency of recent developments in biomedical science. They offer thought experiments and confront readers with their own assumptions about genetic privacy and prompt them to examine these assumptions critically. They reflect and scrutinize public anxieties about potential risks to their genetic data. And unlike abstract analyses of the ethical issues involved, they combine a critical intellectual representation of genetic privacy with an affective dimension that introduces a valuable psychological complexity into debates about how privacy violations affect individuals and families.

As noted in the introduction, public and private spheres are constitutively interdependent and historically interlinked with the intimacy of the family and the reading of novels. As a result, the twin concepts of privacy and intimacy are frequently depicted in the novel in a way that elucidates their imbrication in the surrounding social, political, and economic landscape. Michael McKeon refers to this aesthetic phenomenon as the "internalization" of the public by the private (McKeon 716). This allows us to see genetic privacy as always already bound up with and hence also threatened by social – and in this case biotechnological – conditions outside of the intimate space of the individual or the family. In Weldon's novel, for instance, control over genetic information is intricately tied up with the commodification of citizens'

lives and a feminist resistance to male power over reproduction (Hebert 30-31; Ferreira 12-13). Cloning narratives also closely examine privacy's entanglement with public perceptions of the role of science in society (cf. Marcus 412; Roxburgh and Clayton). The particular strength of a literary-bioethical approach to the issue of genetic privacy is that it connects privacy to multiple levels of society, experience and understanding. In my reading of Hoffman's *The Secret* and Ishiguro's *Never Let Me Go*, this literary-bioethical focus reveals in the texts a sustained concern with the affective consequences of an impaired genetic privacy, especially as it manifests itself in the clones' fractured ability to form meaningful intimate relations and their attempts to combat this through their actions as well as through their forms of narration. In addition, a focus on genetic privacy opens up questions about the particular information economies portrayed in the novels and their often tragic implications for the clones' individual autonomy.

"You have no right to keep this from me!": Privacy and Ownership in *The Secret*

Eva Hoffman's novel *The Secret* is a prime example of how cloning narratives address issues of genetic privacy. *The Secret* was published in 2001 when media attention around the Human Genome Project (HGP) was at its peak. The HGP, which is indirectly referenced in the text (95), sparked the cultural imaginary of the promises of genetic science, from personalized medicine to genetic engineering.² This is reflected in the public fascination with genetic manipulation in *The Secret* as well as in the much darker vision of the cost of such medical advances in *Never Let Me Go*. Another crucial historical background for both novels was the cloning of Dolly the sheep in 1997 which had not only garnered massive press coverage but also led to increasing fears about human cloning (see Hanson, esp. 118-24, 130-32), adding fire to an already inflamed distrust in the decade before 2000 (see Gibbons, Stovall, and Clayton). In this context, the protagonist's struggle with accepting her life as a clone in *The Secret* becomes an acute meditation on the impact of genetic science on individual autonomy and ownership of personal information, especially in a family setting.

The story is narrated by the clone, Iris, whose first-person retrospective account takes the reader from her childhood to her eventual discovery of being a clone and to her subsequent attempts at regaining a sense of control over her life and identity. Her narrational style is characterized by a decidedly analytical tone and she tends to focus on her changing emotive states as she revisits the different stages of her narrative. Her analytical and descriptive voice is occasionally interrupted by her "Adviser" (5), a kind of psychotherapist. At first he seems the intended interlocutor of her narrative but it is soon revealed that her sessions with him also lie in the past, as the narrative voice, in the narrative present, often disagrees with him and is thereby prompted to revisit a particular episode in her life. The clone's retrospective narration directly informs the novel's representation of her loss of familial intimacy and her efforts to regain control over her genetic privacy.

Narrating her childhood and her discovery of her being her mother's clone retrospectively, Iris's description of her intimacy with her mother becomes suspect even in the time before Iris finds out that she lacks genetic privacy. On the one hand, she states that she had an "almost ordinary childhood" (1) and there are numerous references to her comfortable and intimate relationship with her mother. This intimacy is described in what Lauren Berlant frames as the classical hallmarks of intimacy, namely the mostly nonverbal communication between people that works via gestures and touch (Berlant 281): "I loved just driving along with her and looking at her beautiful, unmarred face. Often we didn't talk for hours at a time. We didn't need to" (16). On the other hand, this performance of ordinary and comforting intimacy is

narratively undermined from the very beginning when Iris asks whether she was "a real, an authentic child?" and continues to highlight moments when she felt alienated, a "Weirdness" reflected back in the eyes of others, her aunt Janey among them (1, 13). Iris's intimate relationships are thrown into doubt, foreshadowing the later break with her mother and suggesting a consequence of her lack of genetic privacy already at the level of narration.

The clone's apparent intimacy with her mother is further undercut by the text's numerous images of their conflation through merging or absorption, resulting in what Iris calls their "shared mother-me medium" (6, 38). As Elisabeth Arnould-Bloomfield and Suzanne R. Pucci point out, intimacy relies on some acknowledgement of the foreignness of the other, it is "constituted . . . by an outside that simultaneously join and disjoins" (3). Reminiscent of Arnould-Bloomfield and Pucci's discussion of seventeenth-century mothers who desired their daughters to mirror them completely, the clone's intimacy with her mother can be said to "negate all foreignness, all difference" between them, resulting in an "intimacy between flesh and blood relatives that isn't one" (Arnould-Bloomfield and Pucci 7). This false intimacy – evoked in the text itself by references to Narcissus (171) – further cements the novel's link between a lack of control over one's genetic information and the ability to form intimate relations based on individual autonomy, as the consuming relationship between Iris and her mother is a direct result of this power imbalance.

In addition, her mother's fear of her secret being discovered exacerbates their social isolation. Iris longs for an extended family, yet every time the possibility of social expansion comes within reach, the effort is thwarted by the culture of secrecy cultivated by her mother. When Iris is accepted into a kind of substitute nuclear family in a friend's home, her mother keeps her from seeing them (23). The mother's boyfriend, who assumes a father-role for Iris, leaves when the mother refuses to engage with his hints about Iris's origins (46). In both cases, the mother's desire for privacy causes them further social alienation, aggravating Iris's already felt sense of atomization. Iris becomes "not only marginalized, but actively ostracized" at school (39).

While in this way the novel further outlines negative social consequences from Iris's lack of insight into her own reproductive origins, it is the mother's valuing of her own privacy over her daughter's that proves particularly destructive, keeping knowledge even from the centrally affected party. As Rauscher and Fine's study showed, in families created through artificial reproduction, the parents' privacy is often pitted against that of the children. This asymmetrical access to information is a recurrent theme in the narrative. When her mother continues to refuse to disclose anything about her father, Iris exclaims: "she knew something I didn't, something crucial to me, to my life, to my continuing to breathe. I was determined to wrest it out of her, wrench it out" (47). Iris explicitly frames this asymmetry in legal terms when she argues: "You have no right to keep this from me – I bet you don't even have a legal right!" (58). Her mother refutes any obligation to inform Iris of her genetic origins. She argues: "In a way, it's none of your business. Nobody has any choice about...about who their parents are"; to which Iris replies: "I know I have no choice, but I have to have knowledge" (59). Mother and daughter/clone clash in their opposing claims on control over and ownership of personal information. The first-person narration solicits the reader to sympathize with Iris's position.

The reader's investment in Iris's emotional crisis is consolidated by her anguish following the discovery that she is a clone. Violating her mother's privacy by searching her papers for clues about her father, Iris finds her birth certificate outlining the method of her conception. This discovery plunges her into a crisis of identity: "I was nothing

more than a Xerox of her cellular matter, an offprint of her genetic code" (61). Being a clone of her mother's makes her question her status as a unique human individual and in this way the cloning narrative functions as an allegory for individuation. Here as in numerous other instances in the novel, metaphors become literal. Yet as Iris gains a sense of narrative control over her story, the metaphors appear to revert to their analogical rather than ontological status, a process that underlines the clone's – and the novel's – questioning of the link between genetic material and personal identity. Tied up with this exploration of identity is Iris's struggle to find autonomy and agency in the face of the complete lack of genetic privacy she has just uncovered.

The remainder of the narrative centres on Iris's attempt to regain a level of privacy and control over the use of her genetic information – an attempt mirrored in her control of the narrative as narrator. Directly following her discovery, a sense of powerlessness – symbolized by her feeling of "vertigo" (64) – and betrayal causes her to break with her mother, a blow from which their relationship will not recover and which is symbolized by her leaving the family home never truly to return. The novel here suggests the loss of familial trust and connection as a major risk associated with the violation of genetic privacy within the family.

This privacy violation is explicitly framed as resulting from Iris's lack of consent. The scientist responsible for her conception defends himself from her reproaches by stating that "it was what your mother wanted. We did it with your mother's full consent." (98) When Iris responds by asking: "But what about me?" (98); the geneticist insists that "[s]he was my customer, not you" (100). This exchange reveals that the scientist regards the procedure as an economic transaction and Iris as the product of that transaction. In this logic, it is not surprising that he does not see why the clone's inability to consent should trouble her. Beyond the literal frame of cloning, this scene speaks to an anxiety about an individual's inability to control third-party use of their genetic data, especially in a market setting.

Starting out from this lack of consent and concomitant loss of family, Iris nevertheless manages to forge new family relations over the course of the narrative as she assumes control over the access to her genetic information. First, when searching her mother's documents, she discovers that her grandparents are still alive. After breaking with her mother, she contacts them and thus finds some form of new family belonging.³ Her grandparents are, however, also disturbed by her resemblance to her mother so that Iris's stay with them affords her limited comfort (135). Subsequently, she moves in with her aunt Janey who finally comes to accept her as a family member. Iris recounts that "for a while, we settled into a frictionless, family kind of ease" (215), a sense of intimacy underlined by repeated acts of storytelling about their lives. The first time Janey came to visit young Iris and her mother, Iris was not privy to why their family reunion broke apart. This time, Janey and Iris both know that Iris is a clone so that Iris can actually influence how she wants this knowledge to shape their relationship.

Finally, Iris embarks on the beginnings of a family of her own by entering into a relationship with Robert. The crucial fact about this relationship is that Iris for the first time shared her genetic origins with a third party while being fully in control of the disclosure (243). Tellingly, Iris narrates her emerging intimacy with Robert without foreshadowing how it will play out, as she did with other, unsuccessful attempts at intimacy with Piotr or her grandparents. In addition, her bond with Robert is marked as truly intimate by a recognition of his otherness, his being "Not Me": they were "like two shy particles not quite ready to merge" (264, 244). In this way, Iris reaches an untoward level of autonomy and privacy and, at the end of the novel, is able to formulate a sense of self independent of her mother. A balanced but self-directed combination of

privacy and openness functions for Iris as the optimal approach to overcoming her initial loss of genetic privacy.

Her relationship with Robert follows a heteronormative model of intimacy, which Iris herself identifies as a "cliché" (244). The text's final emphasis on their ideologically-sanctioned relationship appears as a gesture of resistance against the erosion of such forms of intimacy and long-lasting family relationships characterizing the society in the novel. As Iris remarks: "The nuclear family . . . was dead as the dodo by the time I came along." (5) This emphasis on the family in crisis in tandem with a society in thrall to technological innovation, in which reproduction is a matter of capitalist consumption, illustrates techno-capitalism's significant impact on the family as a site of privacy. The novel seems to try and recover a more traditional private sphere unmarked by the intrusion of capitalist-driven genetic science and suggestive of the affective value of intimacy. This conservative gesture indicates an imperative to protect privacy and combat its loss, something Iris has performed as part of her narration. What is more, throughout her articulation of the consequences of an impaired genetic privacy, Iris has also arguably been establishing a kind of intimacy with the reader – whom she also explicitly addresses as "you" (263) –, further extending her performance of her newfound control over her genetic information.

The Collapse of Privacy and the Value of Knowing in *Never Let Me Go*

Kazuo Ishiguro's novel *Never Let Me Go*, published in 2005, also negotiates a lack of genetic privacy through precarious forms of intimacy and an emphasis – hitherto largely overlooked – on the value of having access to information about one's body and its place within the larger power structures of surrounding public institutions. While in *The Secret* Hoffman offers a narrative of gradual emancipation for the clone, the fate of the clones in *Never Let Me Go* is marked by their lasting disempowerment. Ishiguro's protagonist, a clone by the name of Kathy H., retrospectively recounts her life from her childhood days up to the present in "England, late 1990s" as the text epigraphically informs the reader. In the alternative England the novel envisions, clones are raised for the specific medical end of being organ and tissue donors. This biopolitical framing of the clones signals a decisive difference from the familial circumstances in *The Secret*. Here, the public does not linger on the fringes of the family, indirectly rewriting the structures of intimacy by way of a biotechnology that creates different levels of informational control over personal genetic data. In *Never Let Me Go*, the public directly defines the power relations within whatever form of privacy the clones can salvage, down to their very being, thereby blurring the boundaries between the public and the private in the novel, with devastating consequences for the clones.

To the extent that *Never Let Me Go* is a boarding school novel, it is inherently concerned with privacy. Boarding schools as sites of intense communal living challenge students to carve out their own private spaces and identities. In Ishiguro's novel, this dynamic is enriched by the fact that, as clones, the students begin life with the additional lack of privacy over their genetic data. In the novel, the boarding school Hailsham forms a central part of the narrative not only because it is where Kathy H. and her close friends grow up but also because with its happy memories of a family-like collectivity it represents for Kathy a significant space of nostalgia and comfort. Yet despite the positive memories associated with the school, its scarce opportunities for privacy underline early on the clones' informational transparency as genetically engineered beings. In Hailsham, Karla Holloway suggests, "[t]here are no private spaces of retreat or sanctuary. In fact, Ishiguro makes an issue of the loss of the private" (Holloway 73).

This loss of privacy is underlined by the novel's subtle suggestions of surveillance, both at Hailsham and later at the Cottages with "[e]veryone always listening in" (140). Apart from their being surveilled at Hailsham by their teachers, the "guardians", as well as by their peers, the clones "had some form of medical almost every week" (12). This constitutes a form of surveillance that includes their thoroughly medicalized bodies.

As their very being is controlled by an outside force, the clones appear to exist in an in-between sphere where the private collapses into the public. Numerous such public-private spaces at Hailsham illustrate this. The public lunch-queue, for instance, is one of the few places Kathy can speak with Tommy in something approaching privacy (21). And while the pond allows some degree of privacy, they're at constant risk of being watched from the house (23). Even outside and at play, students are rarely alone. This, Nancy Armstrong argues, affords them "a kind of intimacy that is also profoundly social. . . . There is no difference between public and private at Hailsham but altogether different social space" (458). However, the intimacy generated by their socialized privacy is characterized by vulnerability and is indexical of the socio-political and medical powers controlling the clones' existence. This presence of the outside within their intimate spaces continuously points beyond it and towards their lack of agency and control, not only over their genetic data but over the fate of their lives as well.

In *The Secret*, a lack of genetic privacy affects the clone's intimate and family relations; in *Never Let Me Go*, the clones' impaired genetic privacy is more drastically connected to an absence of family altogether. In fact, the experience of any kind of traditional family is poignantly portrayed as an impossible fantasy in the novel. At Hailsham, Kathy often listens to the novel's eponymous song "Never Let Me Go" and imagines holding a baby while dancing (64). Beside the wish for a family of her own, Anne Whitehead additionally sees in Kathy here a desire to be held herself by a mother (Whitehead 67). The scene is also the setting for yet another public-private moment as Kathy is being observed, first unknowingly, by Madame, one of the school's supporters. Madame later tells Kathy that the scene struck her as a tragic emblem of the fundamental divide between their society before and after the trade-off was made between medical cures for a swathe of diseases and the tragic cost of raising clones for that purpose (248-49). The song's conventionalized discourse of lasting love underlines the tragic position of the clones who are non-citizens in a society whose ideologies of intimacy and comfort they crave but can never attain.

Over the course of the novel, the intimacy between Kathy and her friends Tommy and Ruth act as the central marker of the clones' ability – and inability – to form meaningful attachments. Just as in my reading of *The Secret*, using intimacy as a way to gauge the text's affective and agential realities of genetic privacy, and so to excavate its implications for bioethics, requires qualitative, literary-aesthetic attention to how intimacies are produced and represented in the text. The representation of precarious private spaces at Hailsham already suggests a limitation to the clones' intimate experiences. At the same time, their alternative forms of intimacy afforded by the public-private sphere of their existence do provide a real source of comfort for them. For instance, while being watched by her girlfriends, Kathy approaches Tommy to calm him down after some boys had played a prank on him. While Tommy unwittingly flicks away Kathy's hand, her nonverbal gesture symbolizes the beginning of their friendship. His surprise at her empathetic grasp of his feelings in the moment further signals their developing intimacy; though at this point Ruth's embrace after the event is still the dominant marker of intimate comfort (10-11).

The sharing of secrets and intimate knowledge provides another way in which connections of intimacy are established and maintained at Hailsham. As will emerge on a different level as a troubling background to the students' early felicity, a restricted knowledge economy is indeed integral to the school's overall ideology. Secrets are for example constitutive to the "secret guard" game Ruth has invented about the alleged kidnapping of a teacher (45). The sharing of secrets – irrespective of their fabricated nature – binds the initiated students together, Kathy included, as much as the incremental reveal of the secrets by Ruth as the ultimate knowledge-keeper puts her in her preferred position of power. This asymmetrical access to information within the game is analogous to the Hailsham's ideology of telling their students as little as possible about their lives after school, and just as the intimacy afforded by the game finally collapses under the weight of its own pretensions, the school policy of warding off the outside world as long as possible is uncovered as an inverse interiorization, and thus continuation, of the outside's disempowering of the clones. Just as the school's surrounding woods and fences both shield the school's private grounds, they also represent a public biopower that closes off the clones' access to its outside sphere. The text explicitly connects the school fences with those of a "prison camp" (70; for a discussion of additional spaces in the novel that internalize political environments see Rich, esp. 645).

The clones' intimacies are strongest at Hailsham because here they are the most unencumbered by considerations of the future. But already at school, intimations of the power of an outside force over their lives prove detrimental to the clones' intimate bonds. To an extent, the students combat normal adolescent competitiveness and insecurities, which rather bolsters up the sense of healthy intimacies that emerge. As they grow older, however, their looming donations also throw a growing shadow over their lives. While Kathy states that she "*always* knew about donations in some vague way" (75, emphasis in original), she and the others "had done everything to avoid the subject" (76). That the teachers actively encourage keeping up this state of indifference is acknowledged first by Miss Lucy who decides, against the wishes of the headmistress, to make it clear to the students that they need to "understand" that their lives are "completely set out" for them (73); and later by the headmistress herself, when Kathy, Tommy and Ruth come to talk with her at the close of the novel. In Kathy's own historiography, the years before their future donations crept into their consciousness mark a "golden time", after which everything became "more serious, and in some ways darker" (70). Significantly, this time shift also marks for Kathy the end of "the time when Tommy and I would have immediately reported to each other any news" (84), like about Tommy's unsettling conversation with Miss Lucy about his creativity – the students' art being used by the school, unbeknownst to the students, to campaign for their recognition as human beings by the governing bodies of their society. Tommy's reluctance to talk with Kathy about this shows their intimacy to be increasingly fragile and exemplifies how the public's biopower intrudes into the clones' most intimate sphere.

In the remaining storyline of the novel, the clones struggle to regain the sense of intimacy and friendship which they experienced during the early years at Hailsham. However, neither at the Cottages, where they spend a few years before becoming "carers" or beginning their donations, nor after, do they manage to truly overcome the powerlessness that grants them only ever fleeting moments of fulfilling attachment. At the Cottages, Tommy and Kathy slowly begin to take each other into their confidences again, and appear to finally act on their latent romantic feelings for each other. Yet this intimacy shatters when Ruth encourages Kathy to ridicule Tommy's newfound

creativity. Ruth is lashing out as a consequence of her struggle with her lack of power over her future – the clones' preoccupation with finding their genetic originals, or "possibles" (137), had her briefly entertain a fantasy of working in an office. This taken together with the close link between art and Hailsham's efforts to reform public perception of the clones, frames the ensuing quarrel that marks the end of their shared intimacy as a direct consequence of their inability to resist the genetic public infrastructure which brought them into being and continues to control their private lives.

At the close of the novel, Hailsham's ideologically restrictive knowledge economy is criticized by the clones and their inability to control knowledge about their own lives is shown to be among the most traumatic consequences of their powerlessness – their lack of ownership over their own bodies is already a tragic given. Towards the end of her career as carer, Kathy becomes the carer of both Ruth and Tommy. Shortly before she dies, Ruth is grief-stricken about keeping Kathy and Tommy apart and urges them to finally follow up on the rumour that Hailsham students can get a "deferral" of their donations if they can show that they are truly in love (212). Kathy and Tommy indeed embrace their lingering romantic feelings for each other and enjoy an untoward intimacy that now also includes the physical proximity of sex. However, their intimacy continues to be fragile, a melancholy sense of missed opportunities undercutting their happiness, which is always "tinged with sadness" (218; see also Choksey 104). Nevertheless, they manage to approach their former headmistress about the deferral, only to discover that the possibility never existed. Although the rumour had not been started by the governors of Hailsham, Miss Emily and Madame, the false hopes raised by the rumour feed into the larger ideology pursued by the school.

In order to present the clones as fully human to the public, the governors of Hailsham provided them with a liberal-humanist education. Their aim to reform their society's view of the clones appears well-intended and their care of the clones stands in sharp contrast to most other facilities in the country. However, it is precisely because by the end of the narrative the clones clearly appear as fully human that, to the reader at least, their inability to live out the promises of their education is all the more tragic. And it is part of the novel's critique of Hailsham's valiant efforts that the school's education seems complicit in the country's oppression of the clones (see also Armstrong 451). Underlined by the school's closure by the end of the novel, Hailsham's protection from the outside world was always only to be a short-lived reprieve from the public's demands on the clones' bodies and genetic information.

In the context of Kathy and Tommy's conversation with Miss Emily, the school's strategy of protecting the clones by withholding information about their future paths as donors is stressed as particularly traumatizing. For Miss Emily the goal of affording the clones a protected childhood, something that "even now no one will ever take from you" (245), justifies their "*sheltering*" the students from the more distressing aspects of their futures, even lying to them about it (245, emphasis in original). Later in the car, Tommy states that he thinks that Miss Lucy, not Miss Emily, was right trying to tell them about their predetermined futures. This subtle emphasis on the value of unfettered access to information about one's own life and body gives way to a scene that has received little critical attention while arguably presenting the novel's only true act of rebellion against the regime that control the clones' lives. Tommy abruptly leaves Kathy alone in the car and disappears in the enveloping "blackness" (250). Then Kathy hears Tommy screaming. Struggling over the uneven terrain to get to him, Kathy apprehends Tommy in the moonlight, "raging, shouting, flinging his fists and kicking out" (250). Tommy's intense emotive state is the novel's culminating expression of a bottomless disempowerment. And significantly, this expression is a reaction to the

clones' lack of controlling knowledge about their own lives, which thus appears as one of the most devastating forms of powerlessness in the text. The scene's symbolic darkness underlines this inability to know one's own place in the world whereas Tommy's figure in the moonlight suggests his realization of the value of knowledge.

Tommy's rage against an uncontrollable force governing his being is as poignant as it is painfully futile. The scene also emphasizes Tommy as a central figure in the text's overall depiction of resistance against, in particular, the knowledge economy at Hailsham: Kathy suggests that Tommy's earlier tantrums were already rebellions against their fates, "because at some level you always *knew*" (252, emphasis in original). When Kathy embraces him in the moonlight and manages to calm him down, their old intimacy seems to resurge but "the wind kept blowing and blowing at us . . . , it seemed like we were holding onto each other because that was the only way to stop us being swept away into the night" (251). Even at this pivotal moment, of both their interpersonal intimacy and Tommy's rebellion against their social suppression and Hailsham's complicit knowledge economy, an outside force (the wind) threatens their intimate embrace. As a result, their intimacy becomes less an expression of a humanist ideal of true love – as propagated by the rumour of the deferral – but of a "shocking . . . intimate relation animated by sheer devastation" (Berlant 287-88). While this interpretation does not deny Kathy and Tommy a genuine experience of intimacy, it situates this intimacy's fragility within the larger biopolitical landscape of the novel and in particular as a consequence of the clones' lack of control over their genetic information and the integrity of their own bodies.

Tommy's screaming resistance also sheds new light on the widespread critical frustration with the lack of resistance or even critique on the part of Kathy the narrator. Tommy's special status in the narrative is due to his realization, possibly early on, of how both Hailsham and their larger society kept them from accessing the information and power necessary to reclaim an agency that could resist the social institutions of their oppression. Against this background, Kathy's narration is less frustratingly complicit with the powers that dominate her own life, but rather expressive of her inability to put into words what Tommy also could only voice as an inarticulate scream. Her seemingly complicit narrative is thus, as others have also noted (e.g. Griffin 657; Query 156-57), the novel's most consistent critique of the clones' powerlessness, and hence of the society which had robbed them of their power. This aspect of the novel speaks to a societal need for an infrastructure that allows articulations of non-consensual uses of genetic data and other violations of genetic privacy to be heard. The novel's bioethical vision thus entails a concrete policy recommendation.

One way in which Kathy's narrative appears to perpetuate her own disempowerment, Choksey argues, is through her belief in the autonomy granted by the kind of narrative of individual development she has learned at Hailsham and which she imposes on her own narration. It is "the idea that simply having access to knowledge equals fair opportunity to make the best of a bad situation" which keeps her from "imagining other possibilities for freedom", and thus demonstrates "Hailsham's final victory of indoctrination" (Choksey 105). One could add that the one area of knowledge explicitly excluded from Hailsham's humanist ideology, as the previous discussion of Tommy has elucidated, is knowledge about the clones themselves, which once again highlights the school's restrictive knowledge economy and points to its deep ideological contradictions.

Kathy's reluctant narrative, which presupposes information the reader often does not yet have (Query 156; Hillard 109), seems to reverse the power dynamic that underlies the clones' own lack of informational control. For once, the clone has the

power to divulge or withhold information. However, this narrative attempt at regaining a measure of control over her own life and narrative is revealed as precarious. Through her account, Kathy undertakes, with some success, to relive and compact the various moments of intimacy she has felt with her friends, especially during their early years (see also Armstrong 457). Her narration "is a way of forgetting the fragility of their relations with each other, the insubstantiality of their lives and the lurking violence . . . which will end them" (Choksey 105). While memory is a recurrent space for the re-enactment of past intimacies, intimacy also crucially "involves an aspiration for a narrative about something shared, a story about both oneself and others" (Berlant 281, 288). While Kathy's narrative clearly demonstrates such an aspiration, repeated moments when Ruth's and Tommy's memories of events differ from hers (e.g. 45, 74, 75), complicate their shared narrative and thus also the sense of intimacy the narrative creates between them. In this way, the narrative construction of the novel itself points to the precarity of the clones' intimacy which the story has established as resulting from their initial lack of genetic privacy and ongoing lack of control over their bodies.

Clare Hanson suggestively reads the alternative forms of intimacy the clones do manage to carve from their public-private being as quiet acts of rebellion against the biopolitical structures of their creators – quiet because their resistance consists precisely in refusing to engage with these structures (Hanson 145-46). In my own bioethical reading of the clones, I stress the many ways in which even their alternative intimacies break down or remain precarious, pointing to the implied value of privacy, in this case genetic privacy, as a pre-requisite for lasting intimacy. However, Hanson's interpretation importantly raises the question of privacy's normative status, which should not automatically be assumed, especially in the contexts of fundamental digital transformations of personhood which the clones also represent: "The individual disappears, their property (as inherited genetic code) subsumed into extractable components of use-value (as tradable genetic commodity)" (Choksey 90). Genetic privacy as a normative, value-imbued concept might change in the wake of such transformations and fictional clones as in Ishiguro's novel may point to the overcoming of some of liberal humanism's hierarchical structures and divisions. However, in my reading of *Never Let Me Go*, the powerful outside force of the public, the genetic power brokers of the new data economy, who directly profit from the clones' lack of genetic privacy, are an always at least implied presence with which the clones' powerlessness is continuously contrasted. Against this biopolitical setting, whose actors make decisions about the clones merely on the basis of their biomedical information, genetic privacy emerges as a normative concept from the novel. Its value is explicitly inscribed in the novel's emphasis on controlling intimate information about oneself and one's future, and can implicitly be derived from the consequences of its absence, especially from the clones' deeply felt precarity of their most intimate relations.

Conclusion

The critical examination of emerging biotechnology and its impact on society is a vital aspect of bioethics. The novels discussed here provide particular perspectives on the contemporary challenges surrounding genetic privacy, for both individuals and their intimate relations within and beyond the family. These perspectives help accentuate critical risks involved when privacy is threatened, they help excavate social anxieties surrounding the control of one's own genetic data and suggest possible ways to combat already existing privacy harms.

In Eva Hoffman's novel *The Secret*, the central mother-daughter relationship is marred by an asymmetrical claim on the ownership of the daughter's genetic

information. Iris' discovery that she is a clone ultimately leads to her estrangement from her mother. Yet as she regains control over her personal life and data, she also manages to rebuild family relations that had previously fractured as a consequence of the mother's actions, and find fulfilling romantic intimacy with Robert. Hoffman's contribution to bioethical debates about privacy through the figure of the clone is both allegorical, in that the anxiety evoked by cloning represents a similar anxiety aroused by genetic privacy, and literal, in that cloning inherently includes a use of genetic information to which the clone has not given consent.

Ishiguro's *Never Let Me Go* explores the clones' failure successfully to combat their compromised genetic privacy. Not only do the social conditions in which the clones find themselves profoundly limit their agency and ability to form and maintain intimate, never mind family, relations, but Kathy and her friends lack the very ability to voice a critique of this state. Tommy's final scream represents the only true act of rebellion against their oppression and explicitly highlights his lack of control over the most intimate information about his own life as one of the most traumatic consequences of the clones' lack of privacy. This fictional scenario highlights a crucial point for public policy to keep in mind as genetic privacy is ever more at risk. The novel serves as a reminder that one of the most dramatic privacy harms is not an initial infringement of privacy but the inability to do anything about it.

These cloning narratives provide powerful analyses of some of the central concerns of genetic privacy today. These transdisciplinary interpretations combine what in bioethics is considered a conceptual argument with an interrogation of literature's affective-aesthetic dimensions. Making these dimension available for bioethics research entails paying close attention to how something like intimacy is constructed and framed in the individual text's narrative. The force of literary perspectives on bioethical questions then lies in engaging on an immediate subjective level the fundamental anxieties and uncertainties raised by biomedical transformation. In this way, a literature and bioethics perspective can produce new guiding questions and research avenues for empirical bioethical studies, giving new impulses to data-gathering designs and providing scenarios with which to compare and cross-examine existing data. Literary fictions may bring into focus issues empirical data has so far either missed or what might even escape the scope of empirical investigation. The cloning narratives discussed above connect complex notions of privacy, consent and family in the context of genetic research and around the changing forms of intimacy produced by biotechnology's extension into the private sphere. These texts not only highlight genetic privacy as a pressing concern for bioethics scholars and science policy makers today but reveal the issue to have an emotive and psychological depth that crucially shapes its impact on society.

Acknowledgement

This paper was supported by funding from the National Institutes of Health for Vanderbilt's Center for Genetic Privacy and Identity in Community Settings, 5RM1HG009034. I would like to thank my colleagues in GetPreCiSe, especially Jay Clayton, Ellen Wright Clayton, Bradley Malin, Ethan Gibbons, Catherine M. Hammack-Aviran, James Hazel, Sarah Igo, Cythia Porter and Christopher Slobogin.

Notes

1. For information on the database compiled by the GetPreCiSe project at Vanderbilt and its percentage of realist fictions, see Gibbons, Stovall, and Clayton in this special issue.

2. One sign of the high hopes for genetics during this period is the finding of Gibbons, Stovall and Clayton that the decade from 2000-2019 was the only decade in a one-hundred-year period when popular representations of genetics in film and television were more favourable than unfavourable.

3. The effort to forge new kinds of family bonds mirrors a similar pattern among the clones in the television show *Orphan Black*, which is the focus of Casey and Clayton's article in this issue.

Works Cited

- Appelbaum, Paul S. "Assessment of Patients' Competence to Consent to Treatment." *N Engl J Med*, vol. 357, no. 18, 2007, pp. 1834-40.
- Armstrong, Nancy. "The Affective Turn in Contemporary Fiction." *Contemporary Literature*, vol. 55, no. 3, 2014, pp. 441-65.
- Arnould-Bloomfield, Elisabeth, and Suzanne R. Pucci. "Esthetics of Intimacy, Esthétique de l'intime: Introduction." *L'Esprit Créateur*, vol. 44, no. 1, 2004, pp. 3-8.
- Ayala, Francisco J. "Cloning Humans? Biological, Ethical and Social Considerations." *PNAS*, vol. 112, no. 29, 2015, pp. 8879-86.
- Berlant, Lauren. "Intimacy: A Special Issue." *Critical Inquiry*, vol. 24, no. 2, 1998, pp. 281-88.
- Casey, Marcie and Jay Clayton. "Queer Kinship: Privacy Concerns in Orphan Black." *Journal of Literature and Science*, vol. 14, no. 1-2, 2021, pp. 125-139.
- Chadwick, Ruth. "Cloning." *Philosophy*, vol. 57, no. 220, 1982, pp. 201-9.
- Chan, Sarah. "More Than Cautionary Tales: The Role of Fiction in Bioethics." *Journal of Medical Ethics*, vol. 35, no. 7, 2009, pp. 398-99.
- Choksey, Lara. *Narrative in the Age of the Genome*. Bloomsbury, 2021.
- Clayton, Ellen W. et al. "A Systematic Literature Review of Individuals' Perspectives on Privacy and Genetic Information in the United States." *PLoS ONE*, vol. 13, no. 10, 2018, pp. 1-26.
- DeCew, Judith. "Privacy." *The Stanford Encyclopedia of Philosophy*, edited by E. N. Zalta, Spring 2018 Edition, plato.stanford.edu/archives/spr2018/entries/privacy/. Accessed 6 June 2021.
- Ducharme, Jamie. "A Major Drug Company Now Has Access to 23andMe's Genetic Data. Should You Be Concerned?" *Time Magazine*, 26 July 2018, time.com/5349896/23andme-glaxo-smith-kline/. Accessed 11 September 2019.
- Eatough, Matthew. "The Time that Remains: Organ Donation, Temporal Duration, and *Bildung* in Kazuo Ishiguro's *Never Let Me Go*." *Literature and Medicine*, vol. 29, no. 1, 2011, pp. 132-60.
- Erlich, Yaniv et al. "Identity Inference of Genomic Data Using Long-Range Familial Searches." *Science*, vol. 362, 2018, pp. 690-94.
- Elwyn, Glyn et al. "Implementing Shared Decision-Making: Consider all the Consequences." *Implementation Science*, vol. 11, no. 114, 2016, pp. 1-10.
- Ferreira, Maria. *I Am the Other: Literary Negotiations of Human Cloning*. Praeger, 2005.
- Garland-Thomson, Rosemarie. "Eugenic World Building and Disability: The Strange World of Kazuo Ishiguro's *Never Let Me Go*." *Journal of Medical Humanities*, vol. 38, 2017, pp. 133-45.
- Gibbons, Ethan, Isaac Stovall, and Jay Clayton. "Genetics in Film and TV, 1912-2020." *Journal of Literature and Science*, vol. 14, no. 1-2, 2021, pp. 1-22.
- Gill, Josie. "Written on the Face: Race and Expression in Kazuo Ishiguro's *Never Let Me Go*." *Modern Fiction Studies*, pp. 60, no. 4, 2014, pp. 844-62.
- Griffin, Gabriele. "Science and the Cultural Imaginary: The Case of Kazuo Ishiguro's *Never Let Me Go*." *Textual Practice*, vol. 23, no. 4, 2009, pp. 645-63.
- Gurwitz, David. "Data Re-Identification: Protect the Children." *Science*, vol. 339, 2013, p. 1033.

- Gutmann, Amy. "Data Re-Identification: Prioritize Privacy." *Science*, vol. 339, 2013, p. 1032.
- Habermas, Jürgen. *The Structural Transformation of the Public Sphere: an Inquiry into a Category of Bourgeois Society*. 1962. Translated by Thomas Burger, Polity, 2005.
- Hamann, Paul. "Under Surveillance: Genetic Privacy in Margaret Atwood's *MaddAddam* Trilogy." *Journal of Literature and Science*, vol. 12, no. 2, 2019, pp. 62-79.
- Hamner, Everett. *Editing the Soul: Science and Fiction in the Genome Age*. The Pennsylvania State UP, 2017.
- Hanson, Clare. *Genetics and the Literary Imagination*. Oxford UP, 2020.
- Hebert, Ann Marie. "Rewriting the Feminine Script: Fay Weldon's Wicked Laughter." *Critical Matrix*, vol. 7, no. 1, 1993, pp. 21-40.
- Hertz, Rosanna, and Margaret K. Nelson. *Random Families: Genetic Strangers, Sperm Donor Siblings, and the Creation of New Kin*. Oxford UP, 2019.
- Hillard, Molly Clark. "Never Let Me Go: Cloning, Transplantation, and the Victorian Novel." *Journal of Narrative Theory*, vol. 49, no. 1, 2019, pp. 109-134.
- Hoffman, Eva. *The Secret: A Fable for our Time*. 2001. Vintage, 2003.
- Holloway, Karla. *Private Bodies, Public Texts: Race, Gender, and a Cultural Bioethics*. Duke UP, 2011.
- Igo, Sarah. *The Known Citizen: A History of Privacy in Modern America*. Harvard UP, 2018.
- Ishiguro, Kazuo. *Klara and the Sun*. Faber & Faber, 2021.
- . *Never Let Me Go*. Faber & Faber, 2005.
- Marcus, Amit. "The Ethics of Human Cloning in Narrative Fiction." *Comparative Literature Studies*, vol. 49, no. 3, 2012, pp. 405-433.
- Laurie, Graeme. *Genetic Privacy: A Challenge to Medico-Legal Norms*. Cambridge UP, 2002.
- Query, Patrick R. "Never Let Me Go and the Horizons of the Novel." *Critique*, vol. 56, no. 2, 2015, pp. 155-72.
- Rauscher, Emily A., and Mark A. Fine. "The Role of Privacy in Families Created Through Assisted Reproduction Technology: Examining Existing Literature Using Communication Privacy Management Theory." *Journal of Family Theory & Review*, vol. 4, 2012, pp. 220-34.
- Ram, Natalie et al. "Genealogy Databases and the Future of Criminal Investigation." *Science*, vol. 360, 2018, vol. 1078-79.
- Ram, Natalie. "Genetic Privacy After Carpenter." *Virginia Law Review*, vol. 105, 2019, pp. 1357-1425.
- Rich, Kelly. "'Look into the Gutter': Infrastructural Interiority in *Never Let Me Go*." *Modern Fiction Studies*, vol. 61, no. 4, 2015, pp. 631-51.
- Rose, Hilary and Steven Rose. *Genes, Cells and Brains: The Promethean Promises of the New Biology*. Verso, 2014.
- Roxburgh, Natalie and Jay Clayton. "Science and Society in Recent Fiction." *Under the Literary Microscope: Science and Society in the Contemporary Novel*, edited by Sina Farzin, Susan M. Gaines, and Roslynn D. Haynes, Penn State UP, 2021, pp. 21-36.
- Schwartz, Paul M. "Internet Privacy and the State." *Connecticut Law Review*, vol. 32, no. 815, 1999, pp. 815-59.
- Warren, Samuel D., and Louis D. Brandeis. "The Right to Privacy." *Harvard Law Review*, vol. 4, no. 5, 1890, pp. 193-220.

Weldon, Fay. *The Cloning of Joanna May*. 1989. Flamingo, 1993.

Whitehead, Anne. "Writing with Care: Kazuo Ishiguro's *Never Let Me Go*." *Contemporary Literature*, vol. 52, no. 1, 2011, pp. 54-83.