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The Ethics of General Population Preventive Genomic Sequencing: Rights and Social Justice

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Advances in DNA sequencing technology open new possibilities for public health genomics, especially in the form of general population preventive genomic sequencing (PGS). Such screening programs would sit at the intersection of public health and preventive health care, and thereby at once invite and resist the use of clinical ethics and public health ethics frameworks. Despite their differences, these ethics frameworks traditionally share a central concern for individual rights. We examine two putative individual rights—the right not to know, and the child's right to an open future—frequently invoked in discussions of predictive genetic testing, in order to explore their potential contribution to evaluating this new practice. Ultimately, we conclude that traditional clinical and public health ethics frameworks, and these two rights in particular, should be complemented by a social justice perspective in order adequately to characterize the ethical dimensions of general population PGS programs.

Keywords: *child's right to an open future, genomics and social justice, genomic screening, public health genomics, right not to know*

I. INTRODUCTION

Although the *idea* of preventive genomic sequencing (PGS) in the general population is not new (Burke et al., 2001; Khoury, McCabe, and McCabe, 2003), advances in sequencing technology open new possibilities for making

such screening programs a reality. Use of whole genome or whole exome sequencing (WGS/WES) can generate information about genetic variants that indicate significant risk of serious illness that may be prevented or ameliorated by clinical intervention (Bookman et al., 2006; Berg, Khoury, and Evans, 2011). Such variants occur in what are described as "medically actionable" genes (Jarvik et al., 2014; ACMG, 2014) or MAGs (Lázaro-Muñoz et al., 2015).[1] Some hope that an application of WGS/WES in the near future will be to screen members of the general population for MAGs (Evans et al., 2013). PGS of this kind could be used to identify risk of conditions like *BRCA1* and *BRCA2* linked cancers, long-QT (a heart rhythm disorder), Lynch syndrome (increasing risk of colon and other cancers), and hemachromotosis (iron overload disease).[2] In the near future, PGS for MAGs could be regularly offered to primary care patients with no symptoms or family history of disease, made commercially available to members of the general public, or tied to other screening programs such as newborn screening, school sports or kindergarten entry physicals, or preconception carrier screening.

The bioethics literature addressing general population PGS for MAGs is in its infancy. In this article, we contribute to this nascent discussion by: (1) locating such screening as sitting at an intersection of public health and preventive health care, (2) describing the importance of this location for identifying and addressing the ethical issues it raises by focusing on two putative individual rights regarding genomic information, and (3) suggesting the importance of social justice lenses of analysis for interpreting these putative rights in the context of general population PGS for MAGs, and for directing us to consider ethical issues beyond those of individual rights.

II. THE INSTITUTIONAL AND ETHICAL FRAMING OF GENERAL POPULATION PGS

Genetic screening programs are a primary focus of public health genomics. Yet, a significant open question remains as to whether general population PGS for MAGs should be designed under a public health or clinical preventive health care model. In an ethical landscape dominated by the language of individual rights, each institutional setting carries different implications for how those rights are typically perceived and balanced against other claims. When viewed as a preventive *clinical* measure, the ethics of such screening programs may center on potential tensions between individual rights with respect to genomic information and health care professionals' obligations of beneficence and nonmaleficence. For example, patients' rights (especially those concerning "autonomy") are sometimes seen as in tension with the health care professionals' obligations of beneficence and nonmaleficence. As discussed below, in the context of information about MAGs such a tension may arise with respect to a perceived "duty to warn" patients (and families)

about potentially preventable harms that may be caused by deleterious genetic conditions, independently of patient preferences regarding genomic information (ACMG, 2013).

If viewed as a *public health* measure, the ethical issues regarding PGS for MAGs may be understood as primarily concerned with the potential for tension between individuals' rights with respect to their genomic information and the utilitarian goals of public health interventions. According to this "liberty framework" for assessing the moral dimensions of public health policy, individual rights and liberties check the power of public health agencies in order to avoid unjustified paternalism in pursuit of population health goals (Powers and Faden, 2006). The potential for a public health framing of PGS for MAGs to offer a distinctive interpretation of rights from that suggested by the clinical context is clear from a recently proposed interpretation of a "'right not to know' . . . for populations on a public health level" (Allen, Sénécal, and Avard, 2014, 11). Finding the right not to know "informed as it has been by the discussion at the individual level", the authors take the relevant question for such a right at the population level to be "when and to what degree . . . [are] public health authorities granted this discretion" (Allen, Sénécal, and Avard, 2014, 12). In other words, they translate the right of populations not to know as a right of public health authorities not to disclose.

Given the recent surge of interest in public health genomics, it is tempting to consider general population PGS for MAGs as clearly aimed at public health goals. However, there are significant limitations on the use of a public health rationale for general population PGS. Importantly, it is not obvious how such programs are able to promote the general health of the relevant population.[3] They are not (currently) useful for ameliorating or addressing prevalent health conditions (such as diabetes or heart disease), because these conditions are not straightforwardly "caused" by genetic factors in a manner amenable to genomic screening (Janssens and van Duijn, 2008).[4] Nor are the conditions identified "communicable" in the traditional sense, so screening would not straightforwardly lead to a decrease in the presence of the gene or condition in the population through antitransmission measures (although the conditions are heritable, thus raising the specter of reproductive implications for PGS). Moreover, such a program would not promote the public or common good in the same way as smoking-cessation programs or centralized sanitation.

However, general population PGS does share some similarities to newborn screening, which has historically adopted a public health framework and rationale (Grosse et al., 2006). As with newborn screening, universal screening of all potentially affected individuals would be the most efficient and effective way of identifying those who are affected with the relevant MAGs. To achieve "universal" uptake, however, newborn screening typically is either mandatory or employs an "opt-out" model with limited opportunities for parental informed consent. Shortly after birth, individual infants are

given a heel stick and their blood spots are screened as a routine aspect of neonatal procedures within the clinical context.[5] The relative efficacy and efficiency of this method of screening newborns depends on the substantially mandatory nature of the screening, as well as the captive nature of the targeted participants (i.e., neonates in a hospital or birthing center shortly after birth). This is important, because the public health justification for screening for the genetic conditions targeted, in either general population PGS or newborn screening, depends on the ability to catch those relatively few affected individuals by screening the entire relevant population. Arguably, to achieve such universal uptake, the benefit to the population must be seen as outweighing an ethical requirement for fully informed and autonomous consent.

A rather different model for a general population PGS program is offered by mammography or colonoscopy procedures, which are typically recommended at regular intervals within particular age ranges (U.S. Preventive Services Task Force, 2008, 2009). Unlike newborn screening, these adult screening practices are commonly placed under the heading of preventive health care rather than public health, and they have become part of routine clinical care. Also unlike newborn screening, these screening programs are significantly "opt-in," and uptake of the relevant recommendations varies dramatically depending on personal preferences, clinician practices, insurance coverage, and preventive care access (Janz et al., 2007; Schueler, Chu, and Smith-Bindman, 2008; Centers for Disease Control and Prevention, 2010). Such screening practices have the benefit of increasing opportunities for informed consent, allowing individuals to weigh the risks and potential benefits of screening at a personal level. On the other hand, effective prevention is hampered by lack of universal participation.

Prenatal or "preconception" genetic screening and diagnoses may serve as yet further models for general population PGS. Prenatal genetic testing is a complex constellation of procedures, screenings, and tests that vary with respect to the risk of miscarriage, invasiveness, the conditions able to be detected, and the time and setting in which they are offered. Traditionally, the procedures and tests are unified by the aim to determine whether the fetus has genetic or other abnormalities that are known to cause significant health or developmental problems. As with mammography and colonoscopy, most testing is routinely recommended to those who are identified as high risk by "advanced maternal age" or other criteria. However, expansion of population-based prenatal or preconception carrier screening for conditions such as fragile X have been promoted by advocacy, and some professional, groups who propose testing any woman requesting it regardless of family history (see, e.g., National Fragile X Foundation, 2017; American College of Obstetricians and Gynecologists, 2010). This type of screening would be more like general population PGS for MAGs than is traditional

targeted prenatal genetic testing. Further, as noninvasive fetal screening techniques have developed, the potential to have much more information, at less medical risk to the fetus and pregnant woman, has raised new ethical questions and promoted wider screening practices.

The notions of prevention and amelioration are particularly fraught in these contexts. For example, the possibility of prenatal PGS using noninvasive screening techniques, along with expanded carrier screening, may imply that it is appropriate to terminate or forgo pregnancies if the fetus or woman tests positive for MAGs. Here, a public health understanding of prevention of the disorder implies prevention of the life of the individual with the disorder. Others point out that prenatal PGS and expanded carrier screening has therapeutic uses such as ensuring appropriate "fetal surveillance," and aiding decision-making about timing, place, and mode of delivery or conception (Collins and Impey, 2012). In either case, the prevailing (though not uncriticized—see, e.g., Chieng, Chan, and Lee, 2011) professional ethic of genetic counselors has been one of nondirective informing and respect for individual patient decisions. At the same time, genetic testing companies have engaged vigorously in direct-to-consumer advertising of their products, though not direct-to-consumer sales at this time (Jennifer Fishman, communication on 2/1/16).

As new general population PGS screening practices find their way among various settled practices "in the neighborhood," some confusion may arise regarding how to approach and frame the moral concerns at issue. Commentators on the ethics of general population PGS for MAGs face an intersection of moral concerns and traditions from these relevant practices and contexts including: clinical ethics' focus on the promotion and protection of individual patient rights and interests (e.g., respect for autonomy, promotion of individual welfare), consideration of diverse professional norms and perceived obligations (e.g., duty to warn, adherence to nondirective counseling, promoting population health, consideration of minor children's "best interests"), and balance between the general welfare goals of population health and various individual rights and interests (e.g., regarding informed consent, refusal of screening, etc.). Particularly significant is the question of how to interpret and value individual rights commonly evoked in the context of genomic information gathering and sharing: the right not to know and the child's right to an open future. In the next section, we investigate these frequently invoked rights regarding genetic and genomic information alongside consideration of relevant clinical and public health models in order to illustrate both how such rights might be considered in the context of general population PGS for MAGs, and to point to a need for a more expansive ethical framework beyond individual rights.

III. RIGHTS WITH RESPECT TO GENETIC INFORMATION

The Right Not to Know

Article 5(c) of UNESCO's Declaration on the Human Genome and Human Rights states that each individual has the right "to decide *whether or not* to be informed of the results of genetic examination and the resulting consequences should be respected" (UNESCO, 1997; emphasis added).[6] Although the UNESCO declaration parses the right as deciding "whether or not" to become informed, it seems important to distinguish a right to know from a right not to know genomic information. The first requires access to information that may be salient to important decision-making, and the second requires freedom from certain types of information. A right *to* information important to medical decision-making (including whether to enroll in medical research) is uncontroversial as a core tenet of medical ethics and the doctrine of informed consent, at least in most liberal democracies, even given frequent disagreement about what this right entails in practice. (Council of Europe, 1997; American Medical Association, 2006) However, the nature, grounding, and importance of a right *against* (being informed of) certain types of information has remained highly controversial within bioethics (Ost, 1984; Rhodes, 1998; Laurie, 1999, 2014; Andorno, 2004; Chadwick, Levitt, and Shickle, 2014; Knoppers, 2014).[7]

A "right not to know" must be understood as a right *against being informed of particular types of information, in specific circumstances, by particular other persons or institutions*. It implies that some specific persons (e.g., laboratory technicians, clinicians, or allied health professionals) have a duty to avoid presenting some pieces or types of information to those who have explicitly indicated (or about whom there is the right sort of reason to believe) that they do not want this information disclosed to them. Such a right not to know is frequently invoked regarding information about whether one has a genetic predisposition to conditions that may have a dramatic impact on how one plans for and understands one's life or engages with others—especially regarding conditions that can be psychologically or socially harmful to know about (Taylor, 2004; Bortolotti and Widdows, 2011), and with respect to information potentially relevant to reproductive decision-making (Rhodes, 1998). Although a right not to know is frequently discussed in the context of nonmedically actionable genomic information, it is also relevant to medically actionable information, as we shall also describe.

In the context of preimplantation genetic diagnosis, Asscher and Koops (2010) discuss whether the right not to know is violated by the Dutch government's requirement that couples wishing to use the technology in order to select against Huntington's disease first find out their own genetic status. Here, the *public* good of efficiency in provision of health care is explicitly put in tension with the rights of the individuals and families not to be told this

nonmedically actionable genetic information. Regarding medically actionable information, the American College of Medical Genetics and Genomics (ACMG) proposed in 2013 that the right not to know is in conflict with physicians' obligations of beneficence and nonmaleficence, in particular with respect to the disclosure of MAGs identified through opportunistic screening associated with diagnostic use of WES/WGS. In a departure from those who argue that such conflict ought to be resolved by opting for patient autonomy and the "right not to know", they state,

> We recognize that this [recommendation to opportunistically screen for MAGs without patient informed consent] may be seen to violate existing ethical norms regarding the patient's autonomy and "right not to know" genetic risk information. However . . . we felt that clinicians and laboratory personnel have a fiduciary duty to prevent harm by warning patients and their families about certain incidental findings and that this principle supersedes concerns about autonomy. (Green et al., 2013, 568)

In response to feedback from its constituent members, however, the ACMG "updated" its position by supporting patient choice not to receive even medically actionable genomic information (ACMG, 2014).

Whatever values are ultimately at stake in a right not to know,[8] divergent views about the nature and value of autonomy contribute to debates about whether such a moral right exists, and, if it does exist, whether it deserves formal articulation and protection in policy or law (Husted, 2014). Those who understand respect for autonomy as respect for an individual's capacity for rational decision-making may find the idea that we have such a right highly dubious (Ost, 1984; Rhodes, 1998). After all, if adequate decision-making requires the availability of all pertinent information, then purposively avoiding some such information undermines the very capacity that gave us reason to respect an individual's autonomy in the first place. However, if having the information at issue would itself undermine one's ability to engage in deliberative decision-making or might encourage decisions not in fact in line with one's values, as may be the case with certain devastating prognoses (like Huntington's disease) or with highly uncertain or difficult to understand genetic information (such as some carrier status information), then this position could allow for (or even demand) avoidance of that particular information.

On the other hand, if respect for autonomy is understood not primarily as requiring the promotion and protection of a certain kind of adequate decision-making but rather as requiring the protection of a sphere of liberty in decision-making sufficiently robust to include most self-regarding decisions, then more importance may accrue to a right not to know (Andorno, 2004). On this view, the value of respect for autonomy may derive from the individual and collective well-being that is arguably the long-term consequence of the protection of this sphere of decision-making (Malpas, 2005). On this reading of the right, informed by John Stuart Mill and particularly

relevant to the "liberty framework" because of its capacity to curtail incursions of information motivated by public health goals, the right not to know would be justified by appeal to individuals being the best and proper judges about whether particular pieces or types of medically relevant information would facilitate or set back their well-being.

How is the right not to know relevant, then, to thinking about general population PGS for MAGs? If the program is viewed as a public health measure, then an individual right not to know might be invoked within the liberty framework to resist the idea that one could be compelled to participate in the program. If the right not to know is understood as Allen, Sénécal, and Avard (2014, 12) propose as the right of public health authorities to use discretion over disclosure of genomic information, the tension between individual rights and public health interests dissolves, but arguably only by sacrificing the core meaning of the right at the individual level. Promoting the individual's right not to know within a clinical ethics model might motivate, instead, an opt-in model that prioritizes adequate informed consent and decision-making along the lines of a preventive health measure or prenatal or preconception screening.

When PGS for MAGs is considered from a clinical ethics point of view, recognizing a right not to know could influence *how* such screening ought to be offered. We discuss later social justice implications for how such screening ought to be offered. However, in the context of the discussion in this section, a right not to know appears to support offering patients an alternative to a full panel of MAGs, for example, a menu that allows patients to choose for which conditions they are screened (Lázaro-Muñoz et al., 2015). At the same time, it is important to recognize, as is also relevant to our later discussion, that promotion of a formal right not to know alongside institutional or commercial promotion of specific kinds of genomic screening may undermine that right's perceived importance to individuals. For example, women who are "offered" noninvasive prenatal genomic screening by their providers, or who have been directed by advertisements to "ask their provider" about such screening, may be less likely to "choose" actively against such screening.

The Child's Right to an Open Future

Some draw an explicit and tight connection between the adult's right not to know their genomic information and the child's "right to an open future," holding that because adults have the right to either know or not know about their genetic health risks, children must be protected from this information until they are mature enough to make their own decision regarding testing. Otherwise, as adults they will not be able to exercise their right not to know (Dondorp and de Wert, 2013, S15; Hildt, 2009, 147; Borry, Shabani, and Howard, 2014, 20). Similar arguments are frequently marshaled

in defense of the widely shared idea that children should not be screened for adult-onset conditions where any potential medical intervention is also in the adult years (e.g., *BRCA*-related cancers), or for adult-onset conditions for which there is no reasonably effective medical intervention or management (e.g., Huntington's disease or Alzheimer's) (American Society of Human Genetics and American College of Medical Genetics, 1995; American Academy of Pediatrics and American College of Medical Genetics, 2013; Ross et al., 2013).[9]

However, like a right not to know, the child's right to an open future, while intuitively appealing, is not straightforward. Joel Feinberg (1992) introduced the child's right to an open future as part of a cluster of what he calls "rights-in-trust." This concept "refers to rights that are to be *saved* for the child until he is an adult, but which can be violated 'in advance,' so to speak, before the child is even in a position to exercise them" (Feinberg, 1992, 76–77). In other words, a right to an open future protects interests that a child does not currently have, and yet, the right itself can be violated in the present by closing off future options for the adult the child will become.

Such a right is not intended to, nor could it possibly, leave open all or even most spheres of self-regarding decisions until a child can competently make these decisions for himself. Rather, the idea is to protect those decisions that, if made for the child, could severely impoverish his future welfare by closing off morally important future options that he ought be able to pursue should he later decide to do so. Feinberg, for example, discusses the case of *Wisconsin v. Yoder* in which the Supreme Court upheld the right of Amish community members not to send their children to school after 8th grade (U. S. Supreme Court, 1972). The parents claimed that further education violated the community's deeply held religious beliefs and way of life and thus their First Amendment rights, even though the state mandated compulsory education until age 16. The right to an open future argument poses instead that the children's rights are violated by failing to send them to school, since doing so closes off morally important future options that further education leaves open. In another example, in discussing the child's right to an open future in the context of parental claims to a right to choose to have deaf children, Dena Davis (1997) argues that the right to an open future fundamentally protects children's access to that which allows them, as adults, to choose the kind of community to which they belong. She argues, further, that this is an especially morally important and self-constituting decision, at the heart of a liberal democracy, that is denied to those children who would be born deaf through parental choice.

Importantly, in both examples, challenges to a right to an open future potentially come from both community and individual interests (e.g., Amish community or deaf parents' and/or community interests). Although genomic screening of children in a clinical context has typically favored the child's right to an open future where adult-onset conditions are at issue, such a

right has not played a significant role in discussions of public health newborn screening practices historically, as those practices have been aimed at immediately relevant, rather than adult-onset, conditions. These clinical and public health standards arguably are both consistent with the prevailing (though not uncriticized—see, e.g., Diekema, 2004) ethical norm of protection of a child's best interests. However, as the possibility to use WGS/WES in newborn screening has come on the scene, including four studies recently undertaken through funding from the National Institutes of Health (2013), the child's right to an open future may fall in some potential tension with the promotion of their best interests through the public health goals of newborn screening.

The ACMG opinion discussed above illustrates emerging tensions between the "best interests" standard and the right to an open future in a clinical context. Their argument that genetic information obtained through opportunistic screening ought to be returned to children for adult-onset conditions undermines the otherwise nearly universal professional medical and bioethical opinion that children should not be tested for adult-onset conditions. For the ACMG, the argument in favor of disclosure of such findings was an amalgam of concern to warn the child's adult relatives who potentially also carry the same genetic variants and a duty to warn the child, directly, as the relevant information would otherwise need to be intentionally "masked" by laboratories and may not be pursued through later genetic testing when the child is of an age to consent himself (Green et al., 2013, 568). Thus, their argument contends that the health care professionals' obligations to promote the best interests of the child and to nonmaleficence toward his or her relatives override the child's future autonomy rights understood as a right to an open future.

Arguments against genetic testing of children for adult-onset conditions typically hold that, if the child undergoes such testing, he or she will "be robbed of the chance to decide for him or herself, later in life, as an adult, about what he or she wants to know about their genome" (Dondorp and de Wert, 2013, S15). This implies that respect for the child's (future) autonomy centrally involves preserving a sufficiently robust scope of self-regarding decisions about certain types of genetic information. What is not generally provided, however, is an argument that the genetic information at issue is of particular moral importance. Rather, decisions about which genetic tests are permissible for children tend to be made by reference to the immediacy of medical intervention or amelioration. However, these considerations do not address the central tension undergirding a child's right to an open future, between decisions that parents, guardians, and health care providers should make in upholding children's best interests (*including* future interests) and those that children should make themselves (at some future time) as autonomous adults or, alternatively, between public interests in a child's genomic

information and the child's interest in the protection of the future right to refuse such information.

How, then, is the child's right to an open future relevant to general population PGS for MAGs that sit at an intersection between individualized clinical encounters aimed at ending a diagnostic odyssey (such as the opportunistic screening at issue in the ACMG opinion) and broader public health interventions (such as newborn screening)? Likely MAG targets for general population PGS do implicate adult-onset conditions (such as *BRCA1* and *BRCA2* linked cancers or hemachromatosis), while other significant conditions also affect children or young adults (such as long-QT, Marfan syndrome, and certain forms of cancers). As we have discussed, the current literature about ethical issues with predictive genomic screening of children implies that a central issue in screening for MAGs is whether it is morally permissible to test children for conditions likely to manifest in adult ages. According to this understanding of the right to an open future, the relevant question about general population PGS is whether children should receive a separate panel or menu of MAGs for conditions likely to impact them before adulthood, or for which there are preventive or ameliorative measures that can or should be taken in childhood.

However, we have argued that it is more important to consider the moral significance of the particular sphere of decision-making rather than to focus simply on when or whether genomic information can be brought to bear in medical interventions. In this understanding of the right to an open future, the question for general population PGS for MAGs is not merely the age of onset for the conditions in question, or even the age at which preventive or ameliorative measures may be taken, but rather, what such screening implies for closing off particularly valuable kinds of self-determination. Also important are the values and interests (including community interests and the child's own welfare interests) that may be promoted by gaining nonactionable information about adult-onset conditions in children. If, as may sometimes be the case, such screening helps to promote rather than undermine valuable self-determination, then PGS for MAGs for adult-onset conditions *may* not violate a child's right to an open future, regardless of whether it in some way removes some opportunity for future autonomous decision-making. In other contexts, if PGS for adult-onset conditions does violate a child's right to an open future, but promotes significant public health interests, then the "liberty framework" of public health ethics would require balancing the strength of that right against the value of the purported public interest.

IV. GENOMIC RIGHTS AND SOCIAL JUSTICE

For several decades, both the individual interests orientation dominant in clinical ethics, and the liberty framework of public health ethics, have been

significantly challenged by those adopting broad, "social justice" orientations. Calls have been made to expand discussions of the relationship between justice and social determinants of health (Daniels, Kennedy, and Kawachi, 1999), to attend more carefully to how individual clinical interactions are conditioned by social standing (Shim, 2010) and to recognize generally the ways in which developmental, social, and relational factors situate individuals within interactions and institutions (Mackenzie and Stoljar, 2000).

The social justice approach to public health has understood individual liberties and population health goals as part of broader social concerns for equity in securing minimally decent lives for all members of the (relevant) public, and identifying and addressing systematic social bases for inequality and disadvantage (Powers and Faden, 2006; Buchanan, 2008). Congruent with social justice concerns, public health ethics has been influenced in the recent past by the emergence of the capabilities approach to health (Sen, 2002); human rights as a normative framework for promoting community, and not merely individual, health interests (Farmer, 1999; Mann et al., 1994; Braveman, 2016); and a proliferation of empirical research into the social determinants of health (Marmot and Wilkinson, 2005).

Attention to the material and cultural resources necessary to navigate medical institutions and interactions has increasingly been a subject of empirical and conceptual bioethical inquiry within clinical ethics as well. We find the notion of "cultural health capital," introduced by Janet Shim in 2010, especially useful for making sense of this domain. Cultural health capital is "a theoretical framework for understanding how broad social inequalities operate in patient-provider interactions and shape the content and tone of healthcare encounters" (Shim, 2010, 1). Although it is not necessarily the case that lacking cultural health capital and social injustice go hand in hand, the political, civil, and economic inequalities that contribute to low cultural health capital are, arguably, typically unjust.

Cultural health capital is an explicitly relational notion, concerned with how the power of dominant groups can shape institutions and the kinds of attitudes, behaviors, and activities that are valued and taken to be intelligible within particular institutional and social contexts. As the term refers to a "tool kit" of skills and competencies valuable for navigating a particular institution, one's cultural health capital is context specific.[10] Shim argues that, at present in the US health care system, cultural health capital includes: linguistic facility with medical topics and vocabulary, the ability to intelligibly and efficiently communicate health-related information to providers, a proactive attitude about accumulating knowledge and an enterprising disposition about health, the ability to understand and use biomedical information, and an instrumental approach to disease management that privileges belief in the value of self-discipline and self-control.

Taking up this cultural health capital lens, we see that the right *not* to know, as it is presented in the literature on predictive genomic and genetic

testing or screening, may be of primary concern to the relatively privileged, and that focus on it may draw attention away from important social justice questions about the resources required for a positive right *to* know. In particular, a right *not* to know is most salient to those socially situated in ways that allow *access* to the relevant information, *understanding* of what the potential information means, and the interpersonal or social *authority* to insist that this right be respected. A right *to* know medically relevant genomic information has received wide attention, especially in the context of return of incidental findings in a research context (National Bioethics Advisory Commission, 1999; Knoppers, 2014). However, it is generally not discussed in the context of social justice concerns, but rather as a matter, again, of individual rights to particular pieces of information (Forsberg, Hansson, and Eriksson, 2009).

In addition to illustrating ways in which focus on a right not to know might cloak manifestations of social privilege, considerations of social justice may also illuminate the importance of *how* general population PGS for MAGs is offered. Whether such a program is presented as a routine, expected, or regular aspect of health care and whether people are encouraged to seek it out by experts and authorities can influence a patient's perception of whether he has a meaningful choice about his participation.[11] Moreover, communication between the provider and patient is influenced by the particular social identities of the participants. People of color, nonnative English speakers, differently abled persons, people with little formal education, or those with a low socioeconomic status have social identities that frequently differ from those of their physicians. As a result, they may feel less trust in and from physicians with social identities other than their own and may have less productive communication in their interactions (Aronson et al., 2013; Ferguson and Candib, 2002; Gordon et al., 2006; Smith, 2009; van Ryn and Burke, 2000).

In brief, for the patient with high cultural health capital, refusing an offer of PGS for MAGs may seem an act of little significance. For a patient lacking cultural health capital, including with little or no prior understanding of genomics, a fragile hold on the health care system, and lack of a trusting relationship with her health care provider, refusing such genomic screening once "offered" may require overcoming significant interpersonal and institutional hurdles. This suggests that the formal protection of a right to opt-out of a screening program, or to assert one's right not to know in such a context, is not especially meaningful in the absence of the social and material resources one needs in order to exercise this right. It also suggests that we attend to equitable access to, and availability of, genetic counseling or education for any potential general population PGS programs, as well as the nature and quality of the communication between patients and those positioned as authority figures. Small changes in how information is presented can make a great difference in what decisions people make.[12] In particular,

the framing of participation by health care professionals and institutions (e.g., as exceptional or routine, as justified by one's risk status or offered to everyone, and with or without advertisement, information campaigns, and/or relevant policies and inducements) is likely to have a significant influence on how the decision to participate is experienced by individuals.

Similarly, understanding the child's right to an open future with an eye to the social context of individual children and their parents requires recognition that access to the material, social, and cultural resources to make choices in line with that right depends, to a significant degree, on one's social status and on how one's community structures access to the relevant goods. From this perspective, the primary threat to a child's right to an open future comes from lack of access to health-related goods like nutrition, health care, or scientific literacy. Concerns about being provided with genetic information against one's possible future wishes may be relatively peripheral. On the other hand, as with a right not to know, being "given" information not in line with the protection of future autonomy interests may also be harder to resist if a child's parents or guardians are lacking cultural health capital. For example, it is not implausible that only well-informed and "proactive" parents are likely to refuse WGS/WES newborn screening, should such become the norm. This reorientation around considerations of social justice encourages asking not only whether we, as physicians, parents, or public health agencies, should make information about MAGs available for children through PGS, but *how* such information would be made available, and what kinds of educational and support resources should be provided for the entire family along with it.

Reflecting on how best to understand the rights potentially relevant to general population PGS for MAGs suggests that a social justice lens, such as that implied in the idea of cultural health capital, is helpful for assessing the relevant rights. Considerations of social justice are also important for ethical analysis of these programs beyond the traditional focus on individual rights, insofar as such a framework highlights the social features and contexts of the individuals and practices under consideration. We do not suggest that the lens of cultural health capital exhausts the theoretical resources of a social justice perspective, nor that it is necessary for understanding and assessing the institutional and social features of health-related practices and institutions. A similarly powerful integration of social justice concerns from a public health perspective is available, for example, in Powers and Faden's (2006) "twin aim" theory of social justice promoting sufficient levels of well-being along six dimensions as well as combating systemic disadvantages. Also relevant is a focus on rights at the community rather than individual level. For example, when considered with a public health lens on social justice, rights that were understood at the individual level, such as a right not to know or a right to an open future, may be promoted at the group level for those who are systematically disadvantaged by gender, race, ethnicity, culture, sexual

orientation, or global address (Braveman, 2016). Whether taking a clinical ethics or public health ethics perspective, we see the lenses of social justice as providing a necessary resource for interrogating and revising the versions of genomic rights that have become prevalent within the literature on predictive genomic testing.

Health Priorities and Access

One promise of public health genomics is the ability to leverage new medical technologies in service of the public good. However, access to any general population PGS for MAGs program will depend on how it is institutionalized. It will likely be the case that only those with secure access to health care, including sufficient insurance, will be able to participate in any program of this kind. Given the patchwork health care system in the United States, and the financial difficulty of keeping health insurance for many working and middle-class families, the financial cost of PGS for MAGs as an optional clinical service may be well beyond all but the relatively well-off and stably employed (Clayton, 2003).

This raises a significant worry about equitable access to health information and resources. Although not novel in the context of genetic testing (Hall and Olopade, 2006) and genomic medicine more broadly (Moonesinghe et al., 2009), this concern is particularly salient in the general population PGS context. The social disparities that characterize the current political and economic context will give rise to equity-based concerns about these potential programs. Questions that would need to be addressed include how to pay for screening, including how and whether to take into account insurance status, and how screening is institutionally related to follow-up testing and the health services necessary for those who screen positive for particular conditions.

Concern for equitable access to health information and resources also calls for evaluating the potential justifications offered in favor of creating general population PGS programs, particularly if promoted by public institutions. Recognizing the public health domain, following Beauchamp (1976, 1), as characterized by (1) those already socially disadvantaged, bearing the brunt of death and disability from social causes, and where (2) minimizing these risks entails the socially powerful assuming new obligations or relinquishing previous privileges, then "our fundamental attention in public health policy and prevention should not be directed toward a search for new technology, but rather toward breaking existing ethical and political barriers to minimizing death and disability." If we aim to eliminate health inequities, we should focus on addressing known *political, economic, and social* barriers to health access, rather than prioritizing development of new technologies. Public health genomics in the current US health care system, characterized as it is by consumerism and capitalism, and which values patient initiative and

self-management (Shim, 2010), risks being driven more by considerations of what the technology (developed in the context of rare and expensive research and clinical care) can do, and less by what the community needs it to do.

As we have discussed above, a limited uptake of general population PGS for MAGs itself will limit the potential benefits of such a screening program. Access to, and the affordability of, preventive health care and health insurance will inevitably condition not only the extent of uptake in the community, but may lead to a positive correlation between participation and cultural health capital (itself tied to social and cultural identities, and economic status). Pressing questions relevant to a social justice analysis of general population PGS for MAGs programs include whether the evidence base exists to conduct adequate harm-benefit or cost-effectiveness analyses of screening for particular variants in the general population (Prince et al., 2014), the institutional and material feasibility of achieving adequate informed consent for such screening, and how such a screening program, especially follow-up for positive results, would work in the current patchwork healthcare system in the United States.[13]

V. CONCLUSION

Bioethical discussion of various predictive genomic testing and screening practices has prominently featured consideration of individual rights, especially the right not to know genomic information and the child's right to an open future. In the context of public health genomics, ethical issues have been raised largely within the liberty framework, in which individual rights are seen as defeasible checks on pursuit of population health interests. Although the issues raised in those discussions are relevant to general population PGS in considering, for example, whether and when to screen children for adult-onset conditions and whether to offer a menu or panel of MAGs to be screened, they leave to one side significant institutional and systemic concerns such as meaningful access to these technologies and the ways in which an individual's cultural health capital structures their experience of the related health care "choices."

In this paper, we have situated general population predictive genomic sequencing for medically actionable genes (PGS for MAGs) at an intersection of practices and value structures that are well established within clinical medicine and public health including: newborn screening, preventive health screening, and prenatal and preconception genetic screening. We have argued that how such programs negotiate this territory will matter for how they fashion their ethical norms and policies, including the relevant individual rights. We have illustrated our claim by investigating two rights that are commonly invoked in the genomic ethics literature: the right not to

know, and the child's right to an open future. For each right, we have specified how and why such a right might be relevant to PGS for MAGs, but also how the institutional context of interpretation matters for that relevance. By bringing to bear considerations of social justice, we have re-imagined how individual rights might be interpreted and promoted substantively in the context of PGS for MAGs, and we have noted potential expansion of such rights (for example to community rights). However, we have also brought a social justice lens to bear in offering a critique of the efforts to promote PGS for MAGs as a public health measure in light of the substantial resources such programs are likely to incur, and the low likelihood of significant benefit without the type of uptake that itself incurs moral problems by overriding individual autonomy.

NOTES

1. The recently proposed notion of "medically actionable" owes much to the general screening principles proposed by Wilson and Junger (1968). The term "medically actionable gene" typically refers to genes that meet the following criteria: (a) disease-causing variants are sufficiently understood; (b) these variants are sufficiently likely to cause disease (penetrant); (c) the effects of the disease are deleterious; (d) there are some known medical, environmental, or behavioral interventions determined to be sufficiently efficacious and acceptable for preventing and ameliorating disease. For discussion of these criteria and which genes are appropriately considered MAGs, see: Berg et al. (2013); Eckstein, Garrett, and Berkman, (2014); Burke et al. (2001); Bookman et al. (2006).

2. While we use the acronym "PGS" in keeping with the nascent literature on this topic (Lázaro-Muñoz et al., 2015), it is important to acknowledge that the term "preventive" may be misleading for two reasons. At the conceptual level, the genomic condition *itself* obviously cannot be prevented but merely identified. At a practical level, the genomic information gleaned may not be useful for disease prevention, but only for amelioration or mitigation of symptoms or manifestations of the illness or disorder in question.

3. Even with very broad uptake of screening, identification within the general population of those individuals with a genetic variant leading to an otherwise common health condition (e.g., colon or breast cancer) is likely to have only a very small overall effect on rates of morbidity and mortality from those diseases, because most incidence is due to other complex genomic and "environmental" (including socio-behavioral) factors (Evans et al., 2013; Janssens and van Duijn, 2008).

4. Medical geneticists have estimated that general population PGS for MAGs might return positive findings for 0.5–1 percent of those screened (Evans et al., 2013).

5. The Recommended Universal Screening Panel developed by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) in coordination with the Secretary of the US Department of Health and Human Services (DHHS) currently recommends screening for 59 conditions, including conditions targeted by the screening and some other secondary conditions that are identified when looking for these "core" conditions (SACHDNC, 2016; ACMG, 2006).

6. The "right not to know" has been taken up and further articulated by a host of other organizations and agencies, including the World Medical Association and the European Society for Human Genetics. For analysis of this development, see Knoppers (2014).

7. The significance and contours of a right not to know as applied to WGS/WES technology in both clinical and research settings is the topic of a recent *Journal of Law, Medicine & Ethics* special issue. See Knoppers (2014) for a helpful introduction to the issue.

8. Graeme Laurie (2014), for example, argues that it is in fact a right to privacy, rather than self-determination or autonomy, that ultimately justifies a right not to know.

9. As Michael Adams has pointed out to us, another argument against testing or screening children for adult-onset conditions not frequently discussed in the literature is purely practical: given the rate at

which technology and medicine advances, the prognoses and interventions for the genetic disorders at issue may radically change before the child becomes an adult, thereby potentially subjecting him or her to unnecessary worry or even inappropriate intervention by testing before doing so is medically "necessary."

10. Although the language of tool-kit is helpful in explanation of the notion, it may wrongly imply that the use of these competencies is deliberate and strategic. Although particular encounters may be best understood as intentional in this strong sense, cultural health capital is probably better understood as accumulated and deployed in tacit ways through general styles and habits of interaction.

11. How the routinization of testing affects decision-making and judgments about responsibility has been significantly studied in the context of prenatal testing. See Press and Browner (1997) for a particularly formative discussion.

12. See Tversky and Kahneman (1981) for evidence of how the manner in which information is presented can influence individual decision-making.

13. The UNC GeneScreen project is conducting research into each of these questions. This project is conducted by members of UNC's Center for Genomics and Society, an NHGRI-funded Center for Excellence in ELSI Research, which is investigating the ethical, legal and social implications (ELSI) of general population PGS.

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