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The promise of public health ethics for precision medicine: the case of newborn preventive genomic sequencing

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Abstract

Precision medicine aims to tailor medical treatment to match individual characteristics and to stratify individuals to concentrate benefits and avoid harm. It has recently been joined by precision public health – the application of precision medicine at population scale to decrease morbidity and optimise population health. Newborn preventive genomic sequencing (NPGS) provides a helpful case study to consider how we should approach ethical questions in precision public health. In this paper, I use NPGS as a case in point to argue that both precision medicine and precision public health need public health ethics. I make this argument in two parts. First, I claim that discussions of ethics in precision medicine and NPGS tend to focus on predominantly individualistic concepts from medical ethics such as autonomy and empowerment. This highlights some deficiencies, including overlooking that choice is subject to constraints and that an individual's place in the world might impact their capacity to 'be responsible'. Second, I make the case for using a public health ethics approach when considering ethics and NPGS, and thus precision public health more broadly. I discuss how precision public health needs to be construed as a collective enterprise and not just as an aggregation of individual interests. I also show how analysing collective values and interests through concepts such as solidarity can enrich ethical discussion of NPGS and highlight previously overlooked issues. With this approach, bioethics can contribute to more just and more appropriate applications of precision medicine and precision public health, including NPGS.

Keywords

Genomics, precision medicine, public health ethics, newborn screening, solidarity, empowerment

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Introduction

Next generation DNA sequencing (NGS) is increasingly embedded within health care as an aid to both diagnosis and prognostication. It is relatively inexpensive, fast and accurate and has been welcomed by healthcare providers and patients alike. NGS has also attracted significant commercial and political interest and is considered a key technical enabler of precision medicine: tailoring treatments to individuals and their environments to both concentrate benefits and avoid treatment-related harms (Collins and Varmus 2015; Ginsburg and Phillips 2018). Less formally, precision medicine aims to provide the right treatment to the right person at the right time.

Precision medicine and preventive health care are now coming together as precision public health (e.g. Bilkey et al. 2019), which can be described as "…providing the right intervention to the right population at the right time" (Khoury et al. 2016). A key motivation for precision public health is to better deploy 'omics' technologies in populations, to decrease morbidity and optimise population health. This may improve the determination of population susceptibility to genetic conditions, allow superior targeting of therapeutic interventions or better predict what might happen to population health in the future. If employed well, precision public health could lead to better public health, less waste in healthcare provision and less harms from screening.[1]

One potential precision public health initiative is to bring NGS into existing population screening programs.[2] Asymptomatic individuals, such as newborns, could be offered genomic information to enable a more tailored offer of relevant health interventions. Newborns are an obvious target for precision public health because there are existing and highly successful screening programs in place already. Augmenting newborn screening to form 'newborn preventive genomic screening' (NPGS) is under discussion or being trialled in several countries (Ross and Clayton 2019). Contrary to most population screening, NPGS would not be solely focused on detecting conditions. An additional goal would be to set up a so-called 'lifetime health resource' for the screened individual, to be interrogated

[1] There is some debate over what precision public health actually is (e.g. Olstad and McIntyre 2019) and whether it is an appropriate public health exercise at all (e.g. Bayer and Galea 2015). And there is debate (e.g. Brothers et al. 2019) over which testing contexts would qualify as precision medicine. In this paper, I assume that the example I discuss – newborn preventive genomic sequencing – is an example of precision public health, and that precision public health is a form of public health.

[2] It is assumed that any such precision public health initiative would be publicly funded. Additional ethical concerns will arise with precision public health initiatives in a user-funded or personal insurance-based healthcare system. While a full discussion is beyond the scope of this paper, these are questions that public health ethics can help address.

as required to meet the goals of precision medicine. Certain analyses will take place at birth (to inform interventions that may be beneficial in childhood) and then the sequence will be stored for future use.

The need to proceed with caution when it comes to sequencing healthy newborns' genomes, on both scientific and ethical grounds, has been extensively discussed (e.g. Adhikari et al. 2020; Botkin and Rothwell 2016; Friedman et al. 2017; Howard et al. 2015; Johnston et al. 2018; Kemper et al. 2019; Knoppers et al. 2014; Ross and Clayton 2019). Debate also continues regarding the tensions between a child's and their family's interests (Bombard et al. 2009), and attendant issues such as consent and data storage. These discussions also take place against a broader discussion of the use of genomic screening in asymptomatic people *per se* (e.g. Andermann et al. 2008; Burke and Zimmern 2007; Murray 2018). Points in common across this NGS screening literature include personal and clinical utility, workforce capabilities, population health literacy, access to follow-up health care and regulatory concerns such as protection from discrimination (Rothstein 2012).

While these discussions are both insightful and important, to date they have largely taken place drawing on tenets and concepts more commonly found in clinical and medical ethics, such as autonomy and empowerment. These concepts are important, but they are best applied to individuals. This makes it more difficult to consider the collective and interpersonal aspects that arise in precision public health initiatives, beyond a mere aggregation of individual interests. To this end, using the example of NPGS as a case in point, I argue in this paper that precision public health needs public health ethics.

The argument that NPGS (and precision public health more broadly) needs public health ethics is structured into three sections. First, I briefly review the status quo of genomic screening technologies. I then make out the first part of the argument: that relying on concepts more aligned with clinical ethics (such as autonomy or empowerment) is deficient because these concepts limit debate and fail to allow for precision public health to be deliberated as a collective enterprise. In the final section, I advance the positive claim: that concepts and approaches (such as solidarity) more aligned with public health ethics can enrich ethical debate and highlight overlooked issues regarding the collective enterprises of NPGS and precision public health, as well as precision medicine more broadly. By bringing in a public health ethics approach, bioethics scholars can enable a more just and appropriate implementation of precision public health and precision medicine initiatives, including NPGS.

The status of genomics

Introducing NPGS as part of precision public health is generating enthusiasm globally, with existing trends in newborn screening arguably pointing to the future implementation of NPGS. These include the inclination to choose multiplex tests, pressure from patient advocates and industry-advocate or industry-professional partnerships (Pereira and Clayton 2018; Tarini and Goldenberg 2012; Wilson et al. 2007), as well as political enthusiasm to introduce it (Donnelly 2019). Various commercial providers also

already offer forms of NPGS, often marketed as an additional service on top of state-funded newborn screening programs.[3]

Despite this, genomic science and medicine remain subject to several significant limitations (Grody 2019). We need to recognise that the ability to develop technology and routinise its use can outpace the generation of quality evidence to enable critical implementation (Burris and Gostin 2004; Hofmann 2015). These factors need to be recognised in bioethics debate, as ethical analyses that assume the clinical and personal utility[4] of the information genome sequencing generates risk being taken up into policy without those assumptions being interrogated.

Genomic information is complex. The data that will arise from sequencing will be probabilistic, and uncertainty will remain an inherent part of these technologies for some time to come. There are thousands of variants that have yet to be described, leading to calls for caution in the use of genomic screening (Burke 2018; Wilson et al. 2017). The initial description of gene variants in symptomatic populations created assumptions that the variant would be equally predictive in asymptomatic populations. Yet, it has now been shown that caution is needed when extrapolating variant pathogenicity from clinically affected to asymptomatic people (Adams et al. 2016; Burke 2018; Morgan 2018; Wilson et al. 2017).

Indeed, genomic screening could give rise to harms, such as overdiagnosis and over-intervention (Laberge and Burke 2017; Meagher and Berg 2018; Scott et al. 2020; Wilson et al. 2017). Evidence regarding such harms remains nascent and is not yet systematically measured. It will also likely vary depending on population and health system features as well as the condition or conditions screened for. However, examples include a participant in BabySeq whose parents were informed he carried a variant that could cause serious cardiac issues, but in whom no phenotypic signs were identified despite intensive follow-up and ongoing parental worry (Harris 2016). And members of a family who lost an adolescent son to sudden cardiac death underwent unnecessary invasive procedures because a LongQT

[3] At the time of writing, example tests include the BabyGenes™ test from South Genetics (https://southgenetics.com/babygenes/), the Nova™ Postnatal Peace test from sellers including EasyDNA (https://www.easydna.com.au/downloads/postnatalnova.pdf), the Natalis™ test from sema4 (https://sema4.com/products/natalis/), the NextGen test from GenePath laboratories (https://www.genepathlabs.com.au/nextgentest), and the Children's DNA Kit (0-3 years) from TellMeGen (https://shop.tellmegen.com/en/kits/11-dna-test-kid-0-3-years.html). All websites accessed in February 2021.

[4] I endorse the point made by Bunnik et al (2015) that genomic information has personal utility: "if and only if it can reasonably be used for decisions, actions or self-understanding." These authors assert that "perceived utility does not equal personal utility." As such, mere curiosity will not beget utility; while sound clinical judgement might.

variant detected was presumed to be causative – prior to being shown to be absent in the deceased (Ackerman et al. 2016).[5]

Additionally, databases used as references for interpreting variant information still have poor ethnic diversity, which could give rise to inequity in the value of information derived from population screening (Gray et al. 2017; Jooma et al. 2019; Popejoy and Fullerton 2016; Sirugo et al. 2019). The use of tools like polygenic risk scores is also not yet ready for population implementation, including on equity grounds (Hunter and Drazen 2019; Janssens 2019; Martin et al. 2019). For many conditions, the results of genomic testing would be close to pre-test estimates based on background risk. Ultimately, genomic information remains a poor predictor of overall human health.

How the results of genomic screening are described is also important. The end-point of genomic screening is data. This should not be conflated with information, nor with knowledge (Bunnik et al. 2015). Not only are there multiple and confusing senses of 'genetic information', significance creep occurs when it is assumed that information arising from gene sequencing has the same significance as the information encoded in genes (Manson 2006). Genetic information also has an inherent relationship with risk, and so is rarely interpreted neutrally – it has value attributed, which leads to norms and expectations following its receipt (Kihlbom 2018).

These limitations in genomic medicine also hold in the setting of NPGS. Myriad challenges have been identified, including laboratory capacity to handle rapid high-throughput sequencing at population scale, the type of sample that would be needed (as dried bloodspots may not suffice), health professional aptitudes, bioinformatic capacity for variant interpretation, the dynamic nature of the meaning of the information derived and (assuming that a wider range of conditions were screened for) an at-least fivefold increase in the families who receive a screen-positive result (Botkin and Rothwell 2016; Friedman et al. 2017; Johnston et al. 2018). Additionally, problems can arise when parents take up offers of testing from commercial providers (Johnston et al. 2018). This informal implementation could both lead to a distortion of the future evidence base (Burger and Kass 2009) and could reduce the justification for high quality clinical trials.

Of course, this is not to say that genomic sequencing has no value. Obtaining genomic information is undoubtedly important for some patients and their families, in the context of well-defined medical needs. But deploying genomic sequencing to help a patient seeking a clinical diagnosis should not be conflated with the use of sequencing in a public health paradigm. Genomic sequencing will resolve only a fraction of current entrenched public health issues. Ethical assessments of emerging genomic

[5] There is a wider ethical question regarding how to ethically manage the potential for overdiagnosis in population screening. The key issue is whether it is more appropriate to over-diagnose and generate harms, or under-diagnose and not detect everyone. Debate on this continues yet is beyond the scope of this paper to address.

technologies, especially making arguments in favour of mass population sequencing, must account for these limits to knowledge.

The limits of medical and clinical ethics for NPGS

With its origins in the dilemmas of individual clinician-patient relationships, bioethics has been heavily influenced by concepts and issues from medical and clinical ethics (e.g. Dawson 2010; Dawson 2011). Medical ethics draws on implicitly individual-focused concepts such as autonomy, liberty and privacy, with a presumption of non-interference in individual decisions. These individual interests are often cleaved from those of others, and interests that bring us together - generating interdependencies - are overlooked (Jennings and Dawson 2015).

Discussions of NPGS, while highlighting important considerations, reflect these individually focused origins of bioethics. Debate has tended to extrapolate the kinds of dilemmas experienced in clinical applications of genomic sequencing: consent, data storage, managing incidental findings, secondary use in research, recontact (e.g. Friedman et al. 2017; Knoppers et al. 2014; Ross and Clayton 2019). This utilisation of a comparably narrow set of conceptual tools has also been pointed out in relation to ethical discussions of newborn screening more generally, and apportioned to the "tacit *liberal* presuppositions" underscoring much of this debate (van der Burg and Oerlemans 2018, original emphasis).

While scholarship informed by medical and clinical ethics contributes in important ways to ethical debate over NPGS, predominantly using concepts from medical ethics to critically assess population-level interventions overlooks other important considerations, discussed further below. There has yet to be much ethical consideration of NPGS (or precision public health more broadly) that recognises issues at the level of interpersonal collectives, nor a great deal regarding how individuals and groups interact. These omissions seem striking given the population target of NPGS. This shortcoming can be exemplified through a brief discussion of two concepts that commonly arise in discussions of preventive genomic sequencing: autonomy and empowerment.

Autonomy

It might be claimed that population-wide NPGS can be justified on the basis that we can support autonomous decisions of parents for their newborn to have this screening, or that it will be (future) autonomy-promoting for newborns themselves to have their sequence generated at an early stage. Parents, on this kind of reasoning, can be supported to weigh the benefits and drawbacks of testing to arrive at an informed decision as to whether their child should have this screening and whether this is the right decision for their family. If we can facilitate these kinds of decisions to be made well, is it not enough to leave parents to autonomously choose whether to sequence their child's genome?

There are at least two reasons why we should look beyond autonomy. The first is not so much an argument against autonomy, but an argument against focusing only or predominantly on the ability of parents to autonomously choose NPGS. This focus on individual-level parental choices regarding whether to have NPGS (and the implicit assumption that the weighing of relevant factors in such a decision should fall primarily to them) overlooks some of the limitations inherent to liberal individualistic conceptions of medical ethics. NPGS is a population-level intervention, and so it should be critically considered as such. If this claim is correct, then assessing the ethical acceptability of NPGS by considering mainly whether individuals can autonomously choose to have it means we will overlook other important factors, such as the collective harms that populations can accrue from a series of aggregated individual decisions. This could include inequity in access or in test experience (e.g. Jooma et al. 2019), or other harms already noted above: returning false positive results, overdiagnosis or overtreatment. There is also growing recognition that follow-up testing (especially where the utility of an intervention has not been proven) can divert valuable healthcare system resources, as has been observed with direct to consumer genetic testing (Millward et al. 2020).

Second, there are problems with the predominant conception of autonomy that such 'let them autonomously choose' accounts tend to rely on (Dive and Newson 2018). Such 'default' accounts of autonomy negate relational aspects such as the interdependencies inherent to parenting, family and social life – an interdependence that familial genetic information inherently generates. They also do not allow for critical reflection on personal values and overlook that mere provision of information may not always promote autonomy. Additionally, it is far from established that obtaining genomic information increases individual control (Juengst et al. 2012).Concerns have also been raised that what may appear to be an autonomous choice to have a novel health intervention test may actually rest on ambiguous normative foundations (Hofmann and Lysdahl 2008) or may not actually be autonomous at all (Lau and Jaye 2009). While certain accounts of autonomy have recognised problems with individualistic framings in the inherently familial domain of genetics and note the promise of relationality to mitigate this (e.g. Dove et al. 2017), they remain in the minority. As such, population scale NPGS should not be ethically justified on the basis of autonomy alone, especially if a default account of autonomy is employed.

Empowerment and responsibility

NPGS, like other applications of precision medicine, can fairly easily be framed as enabling empowerment – in this case the dual empowerment of parents and the child sequenced. Applying Tengland's (2008) conception of empowerment, NPGS may facilitate parents to feel they are taking control over their child's quality of life and gaining important knowledge and awareness to build self-efficacy. Children themselves will also grow up empowered to manage their own health, informed by their sequence when required.

Yet, while part of empowerment is the endorsement of citizens' capacity to build networks and reduce (unwarranted) professional power, empowerment nevertheless focuses on the voluntary actions of private individuals. It emphasises *individual* choices and the responsibilities that arise from them (Chiapperino and Tengland 2015). In so doing, it fails to recognise external constraints, such as genomics being a hyped technology or there being low genomic literacy (or at least low literacy about the limitations of genomic testing), that are likely to impact liberal individual choices. Therefore, we should be careful not to allow empowerment rhetoric behind NPGS and other precision public health initiatives to justify hype, nor to overlook entrenched issues such as low genomic literacy.

Further, the corollary of empowerment based in individual autonomy is that empowered individuals are ascribed greater responsibility. Juengst writes that personalised medicine sees "the relocation of responsibility for healthcare away from social and political realms and onto the shoulders of patients"(Juengst et al. 2012). Similarly, Kong et al are concerned that an offer of genomic information carries with it an expectation "to become informed and act appropriately based on such knowledge" (Kong et al. 2017). On this reasoning, empowering parents to choose NPGS also generates new responsibilities for them. This change exemplifies broader concerns with individualism in healthcare, under which social determinants for health and factors such as individual health literacy are de-emphasised. Individuals are taken to be the primary responsible actors for their own health and the health of their children, while at the same time overlooking their capacity to handle or exercise this responsibility.

Therefore, the notion of empowered (and responsible) individuals assumes that anyone in receipt of relevant information has available all the necessary insights and resources to rationally process and act prudently on information (Kong et al. 2017; Novas and Rose 2000). It also means that individuals are personally responsible for using genomic sequencing to deliver a version of health that has been pre-defined by others – they are unlikely to have had a stake or a say in creating it (Chiapperino and Tengland 2015). We also need to be mindful that individuals do not always have the resources available to make choices; children especially so. The social construction of choice is relevant: socio-economic, cultural and geographic factors all impact choice too. Collectively, these concerns give rise to a broader claim about the fairness of the onus that new interventions like NPGS places on individuals. 'Empowerment' through NPGS will likely also increase responsibility, and such a responsibility may be neither necessary nor welcomed.

The case for public health ethics in NPGS

So far, I have discussed how precision public health initiatives such as NPGS remain liable to limitations in current science and how a full ethical discussion will be difficult to achieve using only individualistic concepts and approaches from clinical or medical ethics. This arguably risks abandoning parents to their autonomy and over-responsibilising them. Debates over ethics and NPGS are thus, to apply reasoning

from van der Burg and Oerlemans (2018), “hampered by the liberal choice to delegate the responsibility for very difficult issues to parents in the private domain”.

I now set out the positive claim: that NPGS needs conceptual tools and ethical approaches more aligned with (certain conceptions of) public health ethics. These can enrich ethical debate by allowing us to look at issues beyond liberal individualism to critically consider broader systemic and social factors and which will allow us to critically consider NPGS as a collective enterprise.

Public health ethics is yet to gain much traction in precision medicine, perhaps because of concerns around the ‘prevention’ paradigm, or a perception that public health activity necessarily overrides individual control (a central element of precision medicine). It may also be because the prospect of public health applications of genetics and genomics has largely arisen from its foundations as a diagnostic tool. However, the promise of public health ethics has been recognised. Scholars have discussed the possible use of genomic sequencing in a public health context (e.g. Burris and Gostin 2004; Dondorp and de Wert 2013). And some have considered how public health ethics (or important concepts therein, such as social justice and collective benefit) could facilitate ethical consideration in areas such as genomics, biobanking and precision medicine (e.g. Árnason 2012; Johnson et al. 2020; Juengst and Van Rie 2020; Morrissey and Walker 2018; Schaefer et al. 2020; Virani and Longstaff 2015). Additionally, van der Burg and Oerlemans (2018) have called for more attention to concepts familiar to public health ethics in newborn screening, such as interconnectedness, trust, solidarity, reciprocity and caring. Here, I first sketch out an account of public health ethics that will be well-suited to applications of precision public health such as NPGS. I then discuss one value inherent to public health ethics: solidarity; and consider how this value could be operationalised in NPGS.

Public health and public health ethics

According to Dawson, public health ethics must start with a clear articulation of the concept of public health (Dawson 2011). He contends that public health has three central attributes. It is directed to populations rather than individuals (although they are related); it focuses on prevention rather than treatment; and it requires collective efforts for success. Public health, in short, comprises “collective interventions that aim to promote and protect the health of the public” (Verweij and Dawson 2007, p21). Burris and Gostin (2004) add that public health focuses on maximising both the level and satisfactory distribution of health in a population. Being clearer about what public health is allows us to better articulate its aims, and to determine a suitable approach to considering the ethical issues it gives rise to.

These attributes of public health can be applied to NPGS. It is directed to a population (newborns), it has prevention as one aim and it will require a collective effort to succeed. And while the mode of testing (NGS) has similarities with clinical sequencing, its deployment in populations regardless of family history will be distinct. In a clinical test, the proband (index case) will provide their family history to aid variant

interpretation. In NPGS, however, that family history is unlikely to be available; at least at any level of detail. Screening will likely take place using a variety of methods, including whole exome sequencing or by way of a curated variant list that meet standards for use in population screening. Insofar as these approaches are standardised for whole of population use, NPGS can, therefore, be termed a public health activity (ACMG Board of Directors 2019; Brothers et al. 2019).

How well public health ethics can evaluate precision public health activities like NPGS will depend on which approach to public health ethics is used. Dawson supports accounts of public health ethics that go beyond liberal or 'moderated liberal' positions. On his view, values such as individual liberty do not always have priority (Dawson 2011). Rather than focus on non-interference (or least restrictive alternatives) or the acceptability of overriding individual interests, accounts like Dawson's incorporate common goods, public goods and community benefit. They also go beyond seeing populations as aggregates of individual experiences and interests and attend to socio-economic and political factors.

In defending this 'substantive' account of public health ethics, Dawson notes the need for a set of values that aim to capture the collective and *public* nature of public health. People share these values in common and they should be analysed at the level of the community or population (and our inter-relationships) rather than (merely) the individual. With this approach, it is possible to ask and answer new questions, such as what a notion of 'the good' might mean collectively; how collective values and interests such as solidarity, reciprocity and trust can be accounted for and how social justice can be used to overcome inequality (Dawson 2011). If we adopt this collective, substantive approach to public health ethics, it will help us to better determine the kinds of health interventions that it is appropriate to apply at the level of the public (Dawson 2011, applying O'Neill 2002).

Collective values and interests – solidarity

When applied to precision public health interventions like NPGS, a substantive account of public health ethics will both enable the identification of important new considerations and highlight neglected values in possible future implementation. While it is beyond the scope of this paper to discuss all of these considerations and values, in this section I consider the collective value of solidarity. Until recently, solidarity was largely absent from public health ethics debates. As Dawson and Jennings (2012) state, this is likely due to it being a tacit value rather than something superfluous or unimportant.

Dawson and Jennings' account describes solidarity as an underlying and cross-cutting value, necessary to enable any kind of ethical decision. Their foundational dimension for solidarity is the notion of "standing up beside" (Dawson and Jennings 2012, p74); a public action to positively identify with the position of another; whether that other entity is an individual or a group. The action of standing up beside is taken from a position of sympathy and understanding, to attempt to correct disadvantage or injustice. Such solidaristic acts need to take place from a position of "moral concern for that Other" (p74).

This foundational dimension of solidarity is complemented by three relational dimensions: "'standing up for', 'standing up with' and 'standing up as'" (p74). To stand up *for* is to represent and advocate on behalf of the Other. This is especially important when the 'other' cannot speak for themselves. Standing up *with* is to act in accordance with equity and mutuality, while standing up *as* involves adopting a shared commitment to mutual respect (Jennings and Dawson 2015). Importantly, solidarity does not impose direct obligations or duties as other concepts in medical ethics can. Rather, it requires seeing and accepting the social element in all ethical discussion and debate.

Applying this account of solidarity to potential processes and outcomes of NPGS gives rise to two considerations: with whom we should 'stand up'; and how solidarity should inform implementation. Regarding the first consideration, newborns are a group with whom one would have sympathy, and for whom it is important to advocate. We are interdependent with them because they are the future 'us'. They are also clearly a group for whom we have (and should have) moral concern. The social aspect of newborn life is that they will grow up in a healthcare context that has the important task of optimising the health of each individual newborn, but also addressing disparities in health (and future health) between them. So, we should stand up beside newborns.

How might we bring solidarity in to NPGS implementation, to stand up for, with and as newborns? We can stand up *for* them by advocating for screening tests to be designed to optimise their future health, rather than being led by the existence of technology (i.e. a technological imperative). We can push for NPGS to be implemented only when it will add value over and above existing screening programs, and that any benefit is not negated by harms such as overdiagnosis. We can stand up *with* newborns by considering whether NPGS will positively impact health equity, including providing a quality screening test suitable for the whole population, regardless of ethnicity. We can also act to prevent NPGS leading to health system resource drains or detracting attention from other pressing social determinants of health. Standing up *as* newborns will involve designing any future NPGS program to avoid implying that a genomic sequence is an essential lifetime health resource; one that individuals will be compelled to engage with.

We can also stand up beside parents. Standing up *for* parents will involve striving to ensure that NPGS is not championed on the default conception of autonomy; with its attendant emphasis on maximal information and individual responsibility. We could consider alternatives, including carrying out sequencing soon after birth (given the high contact rates between newborns and health systems) but holding the majority of the information 'in trust' until the newborn is older; or, adopting a conservative gene list approach and only employing genetic sequencing when it offers clear benefits over existing biochemical methods. Standing up *with* parents means we should promote access to collective resources that parents need to fulfil their aspirations, and that in so doing their voices are heard and the disparities they are experiencing are addressed. An important consideration here will be scaling up

necessary workforce, including maternal health providers trained in genomics. Standing up *as* parents necessitates that we pay careful attention to messaging around choosing NPGS, including how to engage with those who decline it.

The second consideration is how solidarity can usefully inform the establishment, implementation and evaluation of precision public health initiatives like NPGS. The use of genomics in precision public health needs to account for current limitations of the technology, as well as wider considerations such as health system constraints and other social issues. Yet precision medicine remains a hyped technology (Maughan 2017), relying on framings of individual empowerment and autonomy. While certain instances of genomic sequencing can undoubtedly empower individuals, we need to be careful not to conflate clinical and public health applications of genomics. As discussed above, the latter is not simply a scale-up of the former.

Therefore, the processes and structures of widespread NPGS need to be informed by solidarity at a system level to truly "stand up beside" those who will use it. On such a solidarity perspective, the design and rollout of NPGS needs to be informed by a collective approach, acknowledging interdependencies, vulnerabilities and diversity. Social conditions to promote equity and mutual respect should be articulated in advance. That is, we need to think about newborns and their parents collectively and address wider questions about distribution of health and other relevant goods. We should also avoid NPGS driving the creation of a healthcare need – especially as most health care systems are not yet ready to implement or fully support the repercussions. This will also allow for the putative harms from screening (discussed above) to be prospectively articulated, modelled and mitigated.

Further, considering whether and (if so) how to implement NPGS will also allow us to move away from some of the potential burdens that default conceptions of autonomy give rise to, such as an expectation that more genetic information leads to better health, and the placing of this burden onto individuals. This is not, of course, to say that those who are keen to know more information should be precluded from so doing. It is rather that population needs should drive the screening that is offered; and that this should be thought about at a collective level.

Considering the future implementation of NPGS from the perspective of solidarity thus allows us to bring in numerous considerations that may be overlooked or under-emphasised by ethical approaches that draw more heavily on concepts such as autonomy and empowerment. Solidarity allows us to critically interrogate a range of collective interests and to see these from multiple perspectives. If concepts from public health ethics such as solidarity are appropriately considered in initiatives like NPGS, then – even if it slows its introduction – it will better ensure a more considered and critical implementation, one that will best advance our collective need to "stand up beside" those who need our support. This would not be possible if concepts and approaches from public health ethics were not utilised.

Conclusion

In this paper, I have used the example of Newborn Preventive Genomic Sequencing to consider what public health ethics may offer precision medicine and precision public health. I first explored some of the scientific limits to genomic sequencing, including that it remains subject to certain important limitations, that its use in populations is not the same as scaling up clinical implementation and that it could lead to population harm and waste of healthcare resources. I then made two claims. First, I discussed how NPGS has thus far been debated using individualistic concepts drawn from medical and clinical ethics. These concepts limit debate and overlook important collective aspects of precision public health. Second, I argued that a substantive account of public health ethics, which draws on the main aims of public health (as a 'public' enterprise) and which brings to the fore previously tacit values such as solidarity, can enrich debates over initiatives such as NPGS.

Where does the incorporation of public health ethics take us? One contribution is to critically consider populations, collectives and the shared values and experiences these give rise to rather than only individuals and their interests. It also requires us to critically reflect on the place of technologies such as genome sequencing and their appropriate use at population scale. What, for example, is the population problem that NPGS can solve? Will it allow us to 'stand up beside' newborns and their parents? Addressing questions like these will positively augment bioethics scholarship, to facilitate more just and more appropriate applications of precision medicine and precision public health, including NPGS.

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