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# Permissibility or Priority? Testing or Screening? Essential Distinctions In the Ethics of Prenatal Testing: Response to Chen and Wasserman

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## Abstract

Chen's and Wasserman's suggestion for unlimited whole genome prenatal screening ignores central distinctions, as well as important contributions in the literature, and is backed up by inconsistent arguments. They fail to recognize that their suggestion is less novel than it is held out to be, has been addressed before in various settings, and miss important reasons against their suggestion. They ignore the distinction between using prenatal testing in general and doing it in the organizational form of a screening program. The latter brings many special ethical challenges that are left unaddressed by Chen and Wasserman. One of these is to not only show that some technology is permissible to use for screening, other things being equal, but also demonstrate that it would be defensible use of healthcare resources. This challenge seems to weigh heavily against Chen's and Wasserman's suggestion when asking whether or not it should be given priority (in public, charity as well as business operated settings), supporting limitations of prenatal screening to target more severe conditions available for detection. Chen's and Wasserman's argument against that idea is found to rest on, first, confusion between the issues of permissibility and priority. Secondly, the suggestion that escaping a need to demarcate what to test for is a reason against limiting prenatal screening undermines their own proposal to limit prenatal screening based on probability thresholds.

The intricacies of the ethics of screening are still only partly understood throughout the bioethics and medical community, although some important advances have been made in recent years (Entwistle et al. 2008; Houssami & Miglioretti 2016; Juth & Munthe 2012; McCaffery, et al. 2015; Nijssingh et al. 2017; Parker 2016; Rychetnik et al. 2013, Williams, et al. 2016). To accept a new medical test as responsible medical practice, or to decide to have it on offer at single clinics, raises only a minor part of the ethical issues actualised when one ponders the idea of organising the offering of a test as a societally or commercially run screening program.

This has been recognised within the prenatal testing (PNT) ethics debate by bioethics and public health ethics researchers, and in joint statements by the European and American societies of human genetics (Dondorp et al. 2015; Dondorp & van Lith 2015). Not much of this development is visible in Wasserman's and Chen's article "A Framework for Unrestricted Prenatal Whole-Genome Sequencing: Respecting and Enhancing the Autonomy of Prospective Parents". Approaching the ethics of PNT as if the issue of whether or not to offer an unlimited whole genome variant of PNT is the same issue as the one about if and how to run PNT screening programs of this sort, the article misses central concerns that have been surrounding the ethics of PNT for several decades. One of these concerns, which is also at the heart of the ethics of screening generally, is about *not* whether or not a certain screening program might be (ideally) defensible when considering its direct upsides and downsides (e.g., all the well-known complexities around false positives and negatives, varying predictive values, stigma risks, and so on), but about its opportunity costs or effects. That is, since screening operations are as a rule quite costly, the issue of their *priority* is always a hot potato, and it is therefore by no means settled that a certain screening program is justified just because use of the testing technology it would utilise would be justified.

Chen and Wasserman describe in some more elaborate and technically specified terms a model for an ethically acceptable way of using unlimited whole genome PNT that I sketched and motivated in a recent article (Munthe 2015, especially section 4). This includes the argument about the demarcation

problem that arises for anyone who wants to limit the permissibility of PNT based on the nature of the conditions tested for. Contrary to what Chen and Wasserman suggest (footnote 5), I conceded this argument regarding the issue of *permissible* PNT uses (and elaborated at length the various reasons that have been advanced in the debate for this purpose), but they seem to think that such concession would have to include the priority issue. It does not. Even if you can describe an ideal clinical implementation of a screening program that appears defensible other things being equal, it does not follow that spending resources on this screening program rather than something else is defensible when other things are not being equal. To take a stand on the latter issue, one needs to assess the importance of the aim of the program (in this case assisting parental choice with particular information services) in light of its opportunity costs and other needs that could claim the resources instead. My simple point was that the aim of delivering information for widening reproductive liberty is not by itself a very weighty rationale in view of competing aims (such as preventing or curing disease) for which the rather large amount of resources that would be needed for my own as well as Wasserman's and Chen's suggestions with regard to an ethically acceptable way of offering unlimited whole genome PNT. Moreover, to counter that argument, PNT advocates seem forced to resort to ideas about PNT being about avoiding costly patients in the future, which would undermine the whole idea of an ethically acceptable PNT practice in the first place (Munthe 2015, 1996).

For sure, priority setting always implies demarcation problems, but nevertheless demarcations have to be done, or the use of health care resources will be completely irresponsible. In fact, Chen and Wasserman also make a demarcation, only in terms of probabilities and the epistemic quality of these, in spite of the fact that it is well known that different individuals assess such things very differently and may find very different things important when facing them, so charging others for facing demarcation problems seems a rather moot point. My simple suggestion was to use the same principle for demarcating what health care is to do in the PNT case as when other diagnostic or testing possibilities are considered. The first question is then Wilson's and Jungner's classic query "is this an important health problem?" (Wilson & Jungner 1968). One possibility, which seems to be Chen's and

Wasserman's idea is to characterise the "health problem" addressed by PNT in terms of less than optimal (prospective) parental freedom of choice. That suggestion would close the priority issue quite swiftly, as promoted freedom of choice (in contrast to *respected* freedom of choice) is hardly recognised as a relevant effect in standard healthcare priority setting discussion; there would be no "important" health problem, as there is no health problem (least not one worthy of competing for health care resources). The other possibility is to consider the conditions tested for, and looking at these, it is quite obvious that an unlimited whole genome PNT screening (albeit limited in terms of probability thresholds in line with Chen's and Wasserman's suggestion) would include a large number of predispositions and states that would not be considered important enough for health care to spend resources on in the first place. This is no different to when the triage nurse at the emergency unit tells a patient with a vague headache to go home and have an aspirin as the unit needs to attend to more pressing business. But priority in screening cannot only relate to the importance of the health problem, but has to relate this to resources required. A whole genome PNT screening program thus has to consider also, among those conditions that may qualify as health-relevant, how important it is to spend the resources needed for ethically justified whole genome PNT to look for them prenatally compared to other what could be done with these resources relative to other conditions of ill-health in other areas of health care. This is why I, in light of the fact that PNT almost never contributes to preventing or treating a condition in a patient) made my "radical proposal", that we may be discovering reasons to roll back PNT screening programs as we know them to focus on the most severe (but usually rare) detectable conditions (Munthe 2015). What is severe enough will then, of course, be an issue for debate, but this debate is integral to all health care ethics and hardly a conclusive argument against any suggestion (or it would silence also Chen's and Wasserman's own proposal).

I am thus basically in agreement with Chen and Wasserman on the issue of how an ethically acceptable unlimited whole genome PNT practice may look like, but in sharp disagreement regarding if such a practice should be given priority in view of other health care needs. This priority point may play out differently in public and private health care, however, so let me

close by a few observations about that. In a public system, the priority issue is about the use of public resources and deciding such uses may be guided by a number of considerations which will, however, always be *political*. This is one reason why screening programs run with public money are often controversial (and one particular reason behind the disability criticism against PNT screening). Now, suppose such political reasons make a state (or other public institution) deny Chen's and Wasserman's suggestion; not because it is by itself unjustifiable, but because it does not provide enough bang for the tax dollar bucks. This is, of course, consistent with saying that unlimited whole genome PNT would be lawful if (and only if) it was done according to the Chen and Wasserman specifications. A private provider, operating from an idealistic, or more likely, a business rationale may then adopt the model suggested to meet a demand not attended to by public health care. However, as the model will require quite a bit of resources, also then there will be an issue about priority, although it will be different from the one in the public sphere. A charity will have to look at its guiding statutes, and ask how much money should be spent on this rather than something else, and I suggest this will in most cases create a situation similar to the public sphere issue. A business operation will instead have to look at the combination of the cost, what this implies for pricing, and what effect this may have for customer demand – all in light of that operation's particular profit aim. It not unlikely that the result of such calculations will be that if an unlimited whole genome PNT operation is to be operated ethically (by applying a Chen and Wasserman approach), then it will not be good business since the price needed to offset the cost will quash demand.

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