Preconception testing and screening: Has the HGC covered all the bases?

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Has the Human Genetics Commission (HGC)'s recent report on population-wide preconception genetic testing and screening (1) convincingly demonstrated that this practice raises 'no specific ethical, legal or social principles' that would make population screening unacceptable?

In BioNews 606, I critiqued Dr Callum MacKellar's commentary on the report (2). At the end of my commentary, I alluded to issues I think the HGC didn't address in enough depth. This doesn't mean that preconception screening is unacceptable, but we should pay more attention to these issues before introducing population-wide preconception screening.

I'm concerned about three things. First, the HGC has adopted an 'apple pie' version of reproductive autonomy, viewing this concept as an intrinsic good (an issue Dr MacKellar also recognises). Second, the Commission has failed to justify why it has decided to offer screening to mature school students. Third, the HGC has glossed over the implications of communicating screening results to family members.

The HGC states that 'respect for reproductive autonomy implies that a range of reproductive options should be available' (p1). They claim their proposals for population screening in young people are an extension of screening pregnant women that will increase choice and enhance reproductive autonomy. This seems to suggest that reproductive autonomy is an inherent good.

I don't wish to underplay the right of women or couples to make informed and free decisions before and during pregnancy. But there is significant debate in bioethics and social science about the nature of and appropriate limits to reproductive autonomy, for example the myriad discussions over how women's decisions are influenced. The HGC report seems not to recognise these nuances.

The HGC also implies, somewhat simplistically, that increased choice equals enhanced reproductive autonomy. There are various theoretical and empirical reasons why this is not always the case, which we must recognise before rolling out preconception screening.

Gerald Dworkin, for example, argues that - in society in general - increasing people's choices can impose extra decision-making and social pressure costs, and forces people to shoulder greater personal responsibility for their decisions (3). Dr Abby Lippman also points out that structural constraints on choice (such as a limited time to make a decision) and an over-emphasis on individual decision-making without recognition of our relationships to others can risk women's well-being (4).

The National Screening Committee, in whose hands the HGC report now rests, should explore the concept of reproductive autonomy in greater depth if the report is to become a foundation for policy-making. If testing options are going to be increased then we need to make sure that the additional choices are good ones.

The second issue the HGC underplays is who should be targeted with offers of screening. The Commission discusses offering testing to older school children and young people, but does not justify why this group has been chosen.

Young people may be an ideal group for offering testing and screening programmes involving them in other countries have been successful. Older school children are easily accessible and less likely to have children than young adults.

However, testing in schools may lead to issues of individual freedom versus peer uptake. For example, those offering testing in schools would need to ensure the young person being offered the test was making a genuinely free decision and not following her friends' decisions.

Questions also remain about how well young people understand and remember genetic information and how longer-term follow-up (such as testing future partners if needed) would be managed.

While the practical benefits of testing young people may outweigh these concerns, we should consider alternative population screening targets before deciding on this group. Two alternatives could be offering screening when people apply for a full driving licence or when they register on the electoral roll for the first time. None are perfect, but the target population for preconception screening should be carefully evaluated.

A final practical point is we need to think about how information from large-scale screening is passed on to previously-unaware family members. This may include respecting their 'right not to know' their genetic risk.

The HGC has not convincingly shown that preconception screening carries no specific ethical, legal or social issues; the three I've raised here are some examples. These issues should not necessarily spell the end of preconception screening, but the National Screening Committee should consider all these points before implementing any national policy.

SOURCES & REFERENCES

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