

# Should we be screening future parents for genetic disorders?

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Should public health-care systems provide couples with expanded screening for genetic disorders before they decide to become pregnant? Screening programmes could increase our reproductive choices and autonomy. But there are ethical issues at stake.

"With more choices comes more responsibility, which, in turn, can cause

moral distress. Instead of couples asking themselves if this is the right time to start a family, they could feel pressured to make the 'right' reproductive choices," says Amal Matar, Centre for Research Ethics & Bioethics (CRB) vid Uppsala University, about her Ph.D. thesis based on interviews with Swedish healthcare professionals and healthcare policy experts.

Couples with family history of genetic disorders are offered testing to see if they are carriers of the genes that cause genetic disorders. But what happens if couples planning a baby are offered to screen for up to 1,500 genetic disorders?

In her thesis, Amal Matar interviewed [health care professionals](#) and policy experts. The results show that Swedish experts and professionals believe that this kind of [screening](#) on a larger scale raises ethical concerns. For the individuals, it can affect people's reproductive autonomy. But for us as a society, this kind of expanded genetic carrier screening raises concerns about how we prioritize already limited health-care resources. It could also lead to discrimination and a 'medicalization' of [human reproduction](#), which, according to Amal Matar can have long-term effects on our society and values. Letting medicine control more aspects of your life might not be morally wrong, but some have viewed it as intrusion to their integrity and personal or family space. Her work shows that through the screening process, individuals could find ways to better express their reproductive autonomy.

"In reproductive genetic counselling, healthcare practitioners are expected to help couples make joint reproductive decisions, while at the same time facilitating the individual's reproductive freedom. Two perspectives that are sometimes conflicting," says Amal Matar.

In her thesis, Amal Matar introduces the idea of "couple autonomy," and outlines a number of criteria that should be fulfilled before a joint

decision can be considered autonomous. For example that each partner should be able to express their respective concerns and preferences openly. The couple should also be allowed enough time to weigh the options and reach a joint decision that is acceptable for both of them.

According to Amal Matar, expanded genetic screening before pregnancy could increase our sense of reproductive autonomy. But large-scale implementation potentially threatens the values upon which the Swedish publicly-funded healthcare system is built: Human dignity, equality, and solidarity. She concludes that we need more knowledge about the potential long-term societal effects before considering this kind of genetic preconception expanded carrier screening for the Swedish population. She suggests designing a framework that involves public engagement and societal dialogue about ethical and social issues ensuing from new technologies, can help protect these values.

Genetic testing has become both cheaper and more reliable. It is now possible to screen for up to 1,500 genetic disorders and conditions. Ranging from severe conditions like beta thalassemia (chronic anaemia) and cystic fibrosis, to mild ones, like hereditary fructose intolerance.

Parents can be healthy and unaware that are carriers of the same non-dominant disease gene. If they do, the risk that their child develops the disease is 1 in 4. One group that could potentially benefit from such screening programmes are [couples](#) who are considering having a baby.

If the screening shows there is risk for genetic [disorders](#), the couple can be offered prenatal screening during pregnancy, or in-vitro fertilisation and preimplantation diagnosis, or consider adoption.

**More information:** Matar, Amal (2019): Considering a Baby? Responsible Screening for the Future: Ethical and social implications for implementation and use of preconception expanded carrier screening in

Sweden. [urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-372736](https://nbn-resolving.org/urn:nbn:se:uu:diva-372736)

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