INTRODUCTION

Expanded universal carrier screening (EUCS) entails a population-wide screening offer for multiple disease-causing mutations simultaneously. Although there is much debate about the conditions under which EUCS can responsibly be introduced, there seems to be little discussion about its aim: providing carrier couples with options for autonomous reproductive choice. While this links in with current accounts of the aim of foetal anomaly screening, it is different from how the aim of ancestry-based carrier screening has traditionally been understood: reducing the disease burden in the population. The reasons why the aim of EUCS is presented in terms of ‘autonomy’ rather than ‘prevention’ have not been spelled out in the literature. This paper seeks to fill this gap by considering the morally relevant similarities and dissimilarities between foetal anomaly screening, ancestry-based carrier screening and EUCS. When carrier screening is performed in the prenatal period, enhancing autonomy appears the most appropriate aim of EUCS, as the alternative of ‘prevention through selective abortion’ would urge women to terminate wanted pregnancies. However, when screening is conducted in the preconception period, carrier couples can avoid the birth of affected children by other means than selective abortion, for instance preimplantation genetic diagnosis. To the extent that this increased control over passing on a genetic disorder raises questions of parental responsibility, it seems necessary that the account of the aims of EUCS is wider than only in terms of enhancing reproductive autonomy.

KEYWORDS

expanded carrier screening, preconception carrier screening, procreative beneficence, procreative non-maleficence, reproductive autonomy, responsible parenthood

While this links in with current accounts of the aim of foetal anomaly screening, it is different from how the aim of ancestry-based carrier screening has traditionally been understood:

1Dondorp, W., De Wert, G., Bombard, Y., Bianchi, D. W., Bergmann, C., Borry, P., ... American Society of Human Genetics. (2015). Non-invasive prenatal testing for aneuploidy and beyond: Challenges of responsible innovation in prenatal screening. Summary and recommendations. European Journal of Human Genetics, 23(11), 1438–1450.
Reducing the disease burden in the population. The reasons why the aim of EUCS is presented in terms of ‘autonomy’ rather than ‘prevention’ have not been spelled out in the literature. In this paper, we seek to fill this gap by considering the morally relevant similarities and dissimilarities between foetal anomaly screening, ancestry-based carrier screening and EUCS. By doing so, we intend to provide an ethically sustainable account of the aims of EUCS.

We will argue that, when carrier screening is performed during pregnancy, enhancing autonomy appears the most appropriate aim of EUCS. After all, ‘prevention’ would urge women and their partners to terminate wanted pregnancies. However, when screening is offered in the preconception period, proven carrier couples can choose a wider range of reproductive options than only prenatal diagnosis followed by a possible termination of pregnancy, for instance gamete donation and preimplantation genetic diagnosis (PGD). We will therefore suggest that, to the extent that this increased control over passing on a genetic disorder raises questions of parental responsibility, it seems necessary that the account of the aims of EUCS is wider than only in terms of enhancing reproductive autonomy. Before we move on, we would like to make two notes of clarification. Firstly, we use the term ‘prospective parents’ to refer to persons who intend to conceive in the foreseeable future. Secondly, we focus on the moral rather than the legal responsibilities of prospective parents.

2 | DYNAMICS OF CARRIER SCREENING

Reproductive genetic screening has been offered to pregnant women and prospective parents for more than 50 years. Prenatal screening for Down syndrome first became possible in the late 1960s, when the association between ‘advanced maternal age’ and the prevalence of Down syndrome at birth was identified and a diagnostic test became available. Concurrent with the emergence of foetal anomaly screening, ‘ancestry-based’ or ‘ethnicity-based’ carrier screening programmes were developed among populations with an increased prevalence of specific recessive disorders, for instance carrier screening for beta-thalassaemia in the Mediterranean region and Tay–Sachs disease carrier screening among the Ashkenazi Jewish population. Whereas some of these programmes primarily addressed young individuals or couples who might consider starting a pregnancy, others were offered to couples seeking prenatal care. A more recent development is the promotion of universal approaches that offer screening to all individuals or couples of reproductive age, for instance carrier screening for cystic fibrosis (CF) in the United States. In Box 1, we provide some background information on the carrier screening process.

The availability of new genomic testing possibilities has given carrier screening a new incentive: it allows for efficient screening of tens to hundreds of disease-causing mutations at the same time, usually at much lower costs than separately screening for beta-thalassaemia, Tay–Sachs disease, and so on. As a result, carrier screening panels for the Ashkenazi Jewish population have expanded and now include up to 59 diseases. What is more, such expanded carrier screening (ECS) is expected to provide valuable information for

Box 1 Carrier screening for recessive disorders

It is estimated that there are more than 1300 recessively inherited (autosomal or X-linked) disorders, with symptoms ranging from very mild to severe. Carriers of autosomal recessive disorders have only one copy of the mutated gene and usually do not show any symptoms of the disease. However, when couples carry the same genetic defect, they have a one-in-four risk with each pregnancy that their child will inherit both mutated genes and develop the disease. X-linked disorders are located on the X chromosome. When a woman is a carrier of an X-linked disorder, her male offspring has a one-in-two risk of being affected. If couples want to find out whether they are at risk of having affected offspring, they can opt for carrier screening. The procedure involves providing a blood or saliva sample, which is sent to a genetics laboratory for DNA analysis. Carrier screening can be performed either during or before pregnancy. The latter has the advantage of allowing a wider range of reproductive options than only prenatal diagnosis followed by a possible abortion, including gamete donation and preimplantation genetic diagnosis (PGD). The procedure for PGD is similar to that of in vitro fertilization (IVF), but includes an extra step to check whether the embryos are affected by the defect that causes the genetic condition.
people who do not belong to one of the traditional ‘high-risk’ populations. Although individually rare, it is estimated that one to two in 100 couples of the general population are at risk of having a child affected with a recessive disorder.\textsuperscript{12} To emphasize that broad-scope screening panels for a general population imply a twofold expansion of ancestry-based carrier screening, we will refer to this type of screening as expanded universal carrier screening (EUCS).\textsuperscript{13} EUCS has been offered by commercial laboratories in North America, Australia and Europe for almost a decade.\textsuperscript{14} More recently, it has started to attract the attention of the non-profit part of the health sector.\textsuperscript{15} It has been suggested that, if EUCS becomes widely available, it will eliminate the need for ancestry-based screening.\textsuperscript{16}

Table \ref{table:1} gives a schematic overview of the different variants of carrier screening that are currently offered.

## 3 | AIMS OF REPRODUCTIVE GENETIC SCREENING

In the early days of reproductive screening, prevention, in the sense of reducing the birth prevalence of serious disorders, was seen by many as the primary aim of all reproductive screening programmes, both during and prior to pregnancy. For instance, in an influential paper, public health epidemiologists Zena Stein and Mervyn Susser advocated prenatal diagnostic testing and elective termination of pregnancy as preventive measures to reduce the incidence of Down syndrome at birth.\textsuperscript{17} In the same vein, paediatrician and geneticist Ian Porter argued for ‘prevention through genetic counseling for reproductive options’.\textsuperscript{18} Despite being in line with the aim of most other public health programmes, this emphasis on prevention was soon felt to raise ethical concerns, especially with regard to screening for abnormalities during pregnancy. These concerns were (and are) twofold. Firstly, however much it is stressed that screening should allow women to make their own decisions, it is difficult to see how an account of prenatal screening as aimed at bringing down the number of children born with the relevant conditions would not promote nudging women into making the ‘right’ reproductive choices. Secondly, the ‘prevention paradigm’ has invited the criticism of disability rights’ advocates, according to whom the practice reflects a discriminatory attitude towards people living with the relevant conditions.\textsuperscript{19}

In order to avoid these moral challenges, official accounts of the aim of prenatal screening as given by government bodies or public health authorities have moved away from the language of prevention.\textsuperscript{20} The aim of screening for foetal abnormalities is rather understood as enabling individual women or couples to make autonomous reproductive choices. This not only entails a different measure of success, it also means that any ‘directivity’ on the part of caregivers when providing pre- or post-test counselling, is at odds with the very aim of the practice: caregivers are expected not to influence pregnant women or couples or tell them what to do.\textsuperscript{21}

Interestingly, this debate about the aim of prenatal screening does not seem to have had much influence on how various ancestry-based carrier screening programmes dating from the second half of the last century were – and are – ethically accounted for, notwithstanding the fact that some of these are indeed also offered during pregnancy. In stark contrast to prenatal screening, these programmes have typically been understood as being aimed at reducing the disease burden in the population.\textsuperscript{22} Offering screening with this purpose is regarded as justified in view of either huge societal costs or the suffering of individual children and families, or both.\textsuperscript{23} Boxes 2 and 3 provide examples of how these social-ethical and individual-ethical concerns are reflected in two traditional prevention-aimed carrier screening initiatives.

\begin{table}
\centering
\caption{Schematic overview of the different types of carrier screening, including examples}
\begin{tabular}{|l|l|l|}
\hline
Type & Targeted & Expanded \\
\hline
Ancestry-based & Beta-thalassaemia (Mediterranean region) & Ashkenazi Jewish screening panels \\
& Tay-Sachs disease (Ashkenazi Jewish population) &  \\
\hline
Universal & Cystic fibrosis (U.S. population) & Broad-scope screening panels for a general population \\
\hline
\end{tabular}
\end{table}

12Ropers, H. H. (2012). On the future of genetic risk assessment. Journal of Community Genetics, 3, 229–236.
13Van der Hout, S., Holtkamp, K., Henneman, L., de Wert, G., & Dondorp, W. J. (2016). Advantages of expanded universal carrier screening: what is at stake? European Journal of Human Genetics, 25(1), 17–21.
14Borry, P., Henneman, L., Lakeman, P., ten Kate, L. P., Cornel, M. C., & Howard, H. C. (2011). Preconceptional genetic carrier testing and the commercial offer directly-to-consumers. Human Reproduction, 26, 972–977.
15Cho, D., McGowan, M. L., Metcalfe, J., & Sharp, R. R. (2013). Expanded carrier screening in reproductive healthcare: Perspectives from genetics professionals. Human Reproduction, 28, 1725–1730.
16Edwards, J. G., Feldman, G., Goldberg, J., Gregg, A. R., Norton, M. E., Rose, N. C., ... Watson, M. S. (2015). Expanded carrier screening in reproductive medicine – Points to consider. Obstetrics & Gynecology, 125, 653–662.
17Stein, Z., & Susser, M. (1971). The preventability of Down’s syndrome. HSMHA Health Reports, 86(7), 650–658.
18Porter, I. H. (1982). Control of hereditary disorders. Annual Review of Public Health, 3, 277–319.
19Parens, E., & Asch A. (Eds.). (2000). Prenatal testing and disability rights. Washington, DC: Georgetown University Press.
20Dondorp et al., op. cit. note 1.
21Davis, D. S. (2010). Genetic dilemmas: Reproductive technology, parental choices and children’s futures. Oxford, UK: Oxford University Press.
22Laberge et al., op. cit. note 2.
23Ibid.


Box 2 Beta-thalassaemia carrier screening in Cyprus

In the 1950s, the majority of beta-thalassaemia patients in Cyprus died as a consequence of severe anaemia before reaching the age of 5 years. Thanks to advances in medical technology, the quality of life of affected individuals improved over the years, resulting in a life expectancy of almost 30 years in the 1970s. As a result of these extended life spans, thalassaemia specialists feared that ‘the needs of [their] patients would completely engulf not just the available blood supplies but also the entire budget of the Ministry of Health’. 24

In the early 1980s, the Archbishop announced a quasi-mandatory premartial screening and counselling programme, which was actively supported by various agencies of the Cypriot Government. Couples who wish to get married by the Orthodox Church are required to be screened and counselled by the Thalassaemia Centre and be issued with a certificate. As a result of the screening programme, the number of Cypriot children born with beta-thalassaemia has reduced to virtually zero. 25

With regard to more recently introduced ancestry-based carrier screening programmes, the picture becomes less clear. An interesting example is the pilot that started in 2010 in the Canadian region of Saguenay-Lac-Saint-Jean (Québec), offering carrier screening – both in the preconception and the prenatal period – for four serious recessive disorders that, due to a founder effect, are highly frequent among the region’s population. 26 In a framework document issued by the Corporation de Recherche et d’Action sur les Maladies Héréditaires (CORAMH, a regional grass-root organization set up in the 1990s by parents, researchers and health professionals), the need for such a pilot is explicitly accounted for in terms of a ‘prevention programme’. 27 However, an evaluation report of the same pilot issued by the Québec National Public Health Institute does not refer to the aim of the programme in these terms, but only in those of enabling participants to find out about their carrier status and use that information for well informed reproductive decision making. 28 This clearly echoes the ‘autonomy paradigm’ as developed in the debate about prenatal screening.

Another example of mixed signals is a recent publication about a newly set up ancestry-based carrier screening programme for four disorders in a genetically isolated population in the Netherlands. The authors write that the aim of such programmes is ‘to identify carrier couples with a one-in-four risk of affected offspring, enabling autonomous reproductive decision making, which consequently might reduce perinatal morbidity and mortality’. 29 While the emphasis in this phrase seems to be on promoting autonomous choice, the added clause is revealing. Although suggesting that any relationship with health outcomes is purely contingent, the fact that this is added to a statement about the aim of the programme (something one would certainly not find in official accounts of the aim of prenatal screening) seems to bring out that the ‘prevention paradigm’ is still very much present underneath.

An unambiguous embrace of the autonomy paradigm accompanied the introduction of universal carrier screening in the United States (initially only for single disorders, such as CF; see previous section). Reflecting on this break with the traditional understanding of the aim of carrier screening, Anne-Marie Laberge and colleagues have commented that ‘[t]he focus on information rather than on reduced incidence of disease in CF carrier screening appears to reflect a lack of consensus about the desirability of reducing the incidence of CF births in the U.S.’ Moreover, it suggests that ‘different measures of success will be needed for CF carrier screening’. 30

The aim of EUCS is understood along the same lines. As stressed in programmatic documents and position statements,
this screening proposition does not seek to prevent the conception or birth of children with recessive disorders, but to increase the autonomy of prospective parents by offering them information about a wide array of reproductive risks. As stated by the Public and Professional Policy Committee of the European Society of Human Genetics:

The primary objective of carrier screening in individuals or couples without a known family risk of recessive disorders should be to inform them of possible genetic disease risks in future offspring and of the reproductive options available in order to enable autonomous choices.\textsuperscript{33}

4 | PARENTAL RESPONSIBILITY: THE MISSING PERSPECTIVE IN THE DEBATE

How should this presentation of the aim of EUCS be interpreted from an ethical point of view? Does the embrace of the autonomy paradigm by advocates of EUCS signal a long overdue alignment of the aim of carrier screening for recessive disorders with that of prenatal screening? Or should we say that, at least for certain forms of carrier screening, the prevention paradigm is appropriate? And what would that mean for EUCS?

Although we support the criticism of ‘prevention through selective abortion’, it does not follow, in our view, that ‘prevention through preconception reproductive choices’ is equally problematic. Clearly, the arguments against prevention as pertaining to screening for foetal abnormalities such as Down syndrome also apply to carrier screening during pregnancy: couples who are expecting a child with a recessive disease should not be nudged into terminating a wanted pregnancy, but feel free to ‘make decisions that they judge to be right for them in the circumstances in which they find themselves at the time’.\textsuperscript{34} In the preconception period, however, a prevention-aimed approach may be less problematic. Earlier, we explained that before pregnancy, carrier couples have the largest range of reproductive options at their disposal, including gamete donation and PGD (see Box 1). Passing on a genetic disorder to one’s offspring increasingly becomes a controllable factor in a sense that would not entail emotional and morally sensitive decision making concerning abortion. This increased control over the reproductive risks related to one’s genetic constitution raises questions of parental responsibility. If new testing possibilities enable prospective parents to prevent the conception of children with certain disorders without disproportionate cost to themselves, one could argue that a screening programme explicitly inviting them to act in line with that responsibility need not as such be morally problematic. In fact, it might be morally preferable to one ignoring the very existence of the relevant responsibility.\textsuperscript{35}

Before moving on to a discussion of what this moral responsibility might entail, we would like to make three preliminary remarks. First, parental responsibilities by definition focus on the relation between (prospective) parents and (future) children. Parental responsibility does not involve taking preventive actions for reasons not directly related to the welfare of their children. This means that prevention-aimed carrier screening purely based on public health concerns cannot be justified by referring to parental responsibilities.

Second, it should be considered that the carrier screening process can have quite an impact on prospective parents. Although the testing procedure itself demands little of them (providing a blood or saliva sample), handling knowledge regarding one’s genetic status can be a high burden.\textsuperscript{36} What is more, various studies show that taking preventive measures is by many perceived as a stressful experience; the PGD trajectory is very demanding, bringing emotional, practical and, in some countries, financial strain.\textsuperscript{37} We also need to bear in mind that a significant number of couples choosing this trajectory remain involuntarily childless.\textsuperscript{38} Many couples do not regard gamete donation as a worthy alternative to PGD, as they favour genetic over non-genetic parenthood.\textsuperscript{39} In reflecting on the proportionality of prevention-aimed PCS, these factors need to be taken into consideration.

Third, it is important to note that various couples who learn about their carrier status in the preconception period might still decide to achieve a natural pregnancy. We just argued that couples who are informed about their carrier status when they are already expecting a child should feel free to make their own decisions with regard to pregnancy termination. Depending on the severity of the condition, a wait-and-see approach might be more problematic when carrier couples are aware of the risk of an affected pregnancy already prior to conception. If carrier couples prefer to avoid the birth of an affected child by opting for prenatal diagnosis followed by a possible termination of pregnancy, rather than by means of PGD, they should feel free to follow this route.

\textsuperscript{32}In her book Genetic dilemmas, Dena Davis makes a similar argument. Following her line of reasoning, it could be argued that in the preconception period, situations may occur in which elevating respect for reproductive autonomy above all other values might be morally problematic. As Davis points out, by privileging the reproductive autonomy of prospective parents, ‘there seems no space in which to give proper attention to the moral claims of the future child who is the endpoint of many counseling interactions’. Davis, op. cit. note 21, p. 25.

\textsuperscript{33}Franklin, S., & Roberts, C. (2006). Born and made: An ethnography of preimplantation genetic diagnosis. Princeton, NJ: Princeton University Press.

\textsuperscript{34}Järnholm, S., Thurin-Kjellberg, A., & Broberg, M. (2017). Experiences of pre-implantation genetic diagnosis (PGD) in Sweden: A three-year follow-up of men and women. Journal of Genetic Counseling, 26(5), 1008–1016; Lavery, S. A., Aurell, R., Turner, C., Castello, C., Veiga, A., Barri, P. N., & Winston, R. M. (2002). Preimplantation genetic diagnosis: Patients’ experiences and attitudes. Human Reproduction, 179, 2464–2467.

\textsuperscript{35}Franklin & Roberts, op. cit. note 36.

\textsuperscript{36}Halman, L. J., Abbey, A., & Andrews, F. M. (1992). Attitudes about infertility interventions among fertile and infertile couples. American Journal of Public Health, 82, 191–194.
However, as many expectant parents are already emotionally attached to their unborn child, it is important that, before getting pregnant, carrier couples consider for themselves whether they are prepared to carry the burden of a medically induced abortion. If they consider this to be an undue burden, they might have the moral responsibility to choose a PGD trajectory.

5 | PERSPECTIVES ON RESPONSIBLE PARENTHOOD

We just suggested that the case for the prevention view as connecting with a parental responsibility can more likely be made in the preconception period. The question, however, remains in what cases prospective parents might be held responsible for avoiding the conception of children with a diminished quality of life: only with respect to the worst conditions (for instance Tay-Sachs disease), or also with respect to milder conditions that do not bring unbearable suffering, but nevertheless greatly restrict the range of life plans that humans typically value and choose. Moreover, would a moral obligation to avoid the conception of an affected child imply a prior moral duty to participate in preconception carrier screening (PCS)?

To explore possible arguments for assigning moral obligations to prospective parents with regard to PCS, we will discuss two alternative moral principles that may be used for guiding a couple’s reproductive choices: procreative non-maleficence (PNM) and procreative beneficence (PB). Both principles set limits on a couple’s moral right to reproductive freedom. This right is constrained by moral considerations related to the welfare of the (resultant) child. However, the principles can be distinguished in terms of their different rationalities, i.e., ‘their respective understanding of what counts as a reasonable choice for parents to make’ in light of the available reproductive options. We will argue that the parental responsibilities implied by PNM and PB are not absolute, but prima facie. This means that even if, in principle, prospective parents might have certain moral responsibilities in relation to PCS, there are a number of factors and individual circumstances that may override these responsibilities, such as the emotional and moral burden of taking preventive measures. Although we realize that PNM and PB may be used somewhat differently depending on who is using them, we think that we offer a reasonable interpretation of what these principles may imply with regard to prevention-aimed PCS.

5.1 | The principle of procreative non-maleficence

According to PNM, it is morally wrong to bring children into the world when there is good reason to think that their quality of life will fall below an acceptable threshold. For carrier couples, this would most likely imply that they have a moral duty to avoid conceiving an affected child if the disease under consideration can be expected to make the resultant child’s life intolerable. Because of the difficulty of making general quality-of-life judgements, notably in reproductive contexts, most advocates of PNM are very cautious in labelling a life as being of ‘negative quality’. They defend that this label can only be applied to diseases that ‘exhaustively determine the child’s future’, in other words, to diseases that hinder the child in developing or doing any of the things that persons normally do. This is most evident in cases in which a person suffers from a combination of profound cognitive and physical disabilities. As bioethicist Henrika Clarkeburn articulates it: ‘I propose that the combination of continuous and non-palliative pain and lack of opportunities to develop a continuous self, constitutes life worse than non-existence.’ Only a limited number of recessive conditions fall into this category, for instance Tay-Sachs disease and Canavan disease. As long as there is no treatment available, affected children die in infancy or (early) childhood. During their short lives, they suffer from impaired mobility, intellectual disability or deterioration of the nervous system. Some diseases that only cause severe physical suffering may also be candidates, for instance Herlitz junctional epidermolysis bullosa. Of those affected, 87% die in the first year of life.

A complicating factor in assigning moral obligations to carrier couples by referring to unbearable suffering is that many recessive diseases have a variable expression. For instance, a study by Goker-Alpan and colleagues has demonstrated that the clinical course and outcome observed in patients identified with neuronopathic Gaucher disease ‘varied from young children with severe systemic and/or nervous system involvement that led to early death, to relatively asymptomatic college students’. Based on PNM, it would be very problematic to defend that carrier couples should take preventive measures if the clinical significance of findings remains unclear.

Following PNM, it could thus be argued that carrier couples of the most severe recessive disorders have a moral duty to avoid the conception of affected offspring, provided that the disorders have a clear genotype–phenotype correlation. Does this also mean that carrier couples by referring to unbearable suffering is that many recessive diseases have a variable expression. For instance, a study by Goker-Alpan and colleagues has demonstrated that the clinical course and outcome observed in patients identified with neuronopathic Gaucher disease ‘varied from young children with severe systemic and/or nervous system involvement that led to early death, to relatively asymptomatic college students’. Based on PNM, it would be very problematic to defend that carrier couples should take preventive measures if the clinical significance of findings remains unclear.

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disorders is rather low. Therefore, it would be disproportionate to expect that all couples participate in carrier screening in order to avoid the conception of only a few severely affected children: presenting PCS as a ‘reproductive code of conduct’ would be too high a price. Following this line of reasoning, the moral duty to avoid intolerable suffering in one’s children would not generate a universal obligation to test for the worst recessive diseases; this obligation would only apply to couples with a known increased risk of passing on such a disorder. This first interpretation of PNM (PNM1) would thus lead to a prevention-aimed carrier screening proposition that is neither expanded nor universal: it merely demands that couples who have ‘good reason to assume that [they] belong ... to a group with an elevated genetic risk of severely afflicting future offspring’ undergo PCS, and, if found to be a carrier couple, avoid the conception of an affected child. Here, we would like to make a critical note as well: ‘increased carrier risk’ is a relative concept. This is clear if we look at the incidence of Tay–Sachs disease among members of the Ashkenazi Jewish population. Compared with the general population, they are ten times more likely to be carriers of this lethal disorder, than non-members.48 Sheer evolutionary pressures have led to the establishment of a carrier population of Ashkenazi Jews, whose life expectancy is not worse than the life expectancy of the general population; women who are carriers of Tay–Sachs disease have an ‘increased carrier risk’ as defined by the Ashkenazi Jewish population. Presenting this proposition would thus lead to a prevention-aimed PCS panel that extends to ‘at risk’ couples only. However, based on PNM, one could also argue that the moral duty to participate in PCS is not related to the risk of being a carrier couple, but merely depends on the severity of the disease under consideration, and therefore extends to all couples who wish to have children. Clarkeburn is an advocate of this position: ‘If a condition which is worse than non-existence were identified, the parental duty of [PNM], in a moral sense, would extend even to those parents with only a minimal chance of having a child with such a condition.’ This example shows that it is not obvious what level of risk constitutes a ‘good reason’ for participating in prevention-aimed PCS, unless one’s offspring will have a worse life than the lives of other children a couple could have.

5.2 The principle of procreative beneficence

According to some philosophers, couples have a moral duty to avoid the conception of children not only in cases dealing with unbearable suffering, but in all situations in which they can choose between a ‘less’ and a ‘more’ advantaged child. One of them is Julian Savulescu. He claims that we need a more comprehensive principle, to which he refers as the ‘principle of procreative beneficence’. This maximizing principle suggests that couples who have decided to have a child ‘have a significant moral reason to select the child; of the possible children they could have, whose life can be expected ... to go best or at least not worst than any of the others’. The phrase ‘significant moral reason’ indicates that PB, like PNM, is a prima facie rather than an absolute moral obligation; it may be trumped by competing moral considerations, including ‘the welfare of the [prospective] parents, of existing children, and of others, possible harm to others, and other moral constraints’. Such constraints may, for instance, emerge from a couple’s perspective of in vitro fertilization (IVF) and the moral status of embryos. An appeal to ‘opposing moral reasons’, however, is not justifiable if a child’s life can be predicted to be intolerable. According to Savulescu and Kahane, ‘parents ... should be prevented by law from selecting children whose lives are expected not to be worth living’.53

What are the moral implications of PB for carrier couples? The principle would instruct them to avoid passing on a genetic defect to their offspring, provided that a child born with it can be expected to have a worse life than the lives of other children a couple could have. Using the terminology of Allen Buchanan and colleagues, PB tells carrier couples to avoid conceiving an affected child if the condition under consideration is likely to affect ‘general-purpose means’, i.e. capacities that are ‘useful and valuable in carrying out nearly any plan of life or set of aims that humans typically have’. Examples of such capacities are the ability to hear, see or walk. Although individuals lacking these capacities may still have satisfying and valuable lives, ‘the loss of a general-purpose capacity ... at the least significantly diminishes the range, and makes more difficult the pursuit, of life plans that humans value and choose.’ Savulescu further argues that PGD is the preferred way of selecting the most advantaged child since ‘selection by abortion has greater psychological harms ... and these need to be considered’.

What are, according to PB, the moral duties of prospective parents with regard to PCS? In the absence of overriding moral considerations, the principle would instruct all of them, regardless of their individual carrier risk, to test for all genetic traits that might have a negative impact on the well-being of the resultant child. This means that the screening panel needs to include a wide array of genetic conditions, ranging from severe to relatively mild ones. The prevention-aimed screening panel endorsed by PB would thus be much broader than the one suggested by PNM2. Figure 1 provides a schematic overview of the prevention-aimed PCS panels based on PNM and PB.

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51Bonte et al., op. cit. note 4, p. 9.
52Gross, S. J., Fletcher, B. A., Monaghan, K. G.: Professional Practice and Guidelines Committee. (2008). Carrier screening in individuals of Ashkenazi Jewish descent. Genetics in Medicine, 10(1), 54–56.
53Clarkeburn, op. cit. note 44, p. 402.
54Savulescu, J., & Kahane, G. (2009). The moral obligation to create children with the best chance of the best life. Bioethics, 23(5), 274–290.
55Ibid: 278.
56Ibid: 279.
57Buchanan et al., op. cit. note 40, p. 167.
58Ibid: 168.
59Savulescu, J. (2001). Procreative beneficence: Why we should select the best children. Bioethics, 15(5-6), 413–426.
PB does not provide strong justifications that prospective parents have a prima facie moral duty to participate in a prevention-aimed pre-conception EUCS programme. Savulescu and Kahane argue that their principle can be defended on ‘wide person-affecting grounds’ as well as ‘impersonal grounds’. According to the wide person-affecting view, ‘our reason to select the child with better prospects is that that child will benefit more than the other would by being caused to exist’. So, if a couple can choose between an embryo free of genetic diseases (A) and an embryo with a mild hearing deficit (B), the motivation for transferring A would not be that this would be beneficial to the child who will develop from A; if B were transferred to the womb, an entirely different child would come into existence. The reason for selecting A would rather be that ‘A’s interests will be better met by A’s life than B’s interests would be met by B’s life’. The impersonal version of PB defends that ‘selecting the most advantaged child would make the outcome better, even if it is not better for the child created’. This position is based on the Parfitian idea that, ‘even if no particular individual benefits from PB and the increased quality of life that following PB creates, the world is somehow a better place as a result of the creation of these better lives.’ In our view, neither versions of PB are convincing. Earlier, we argued that parental responsibilities by definition focus on the relation between (prospective) parents and their (future) offspring.

As the moral duties implied by the wide person-affecting and the impersonal views of PB are not directly related to what parents are due to their children, we do not see how prospective parents could be expected to act in line with these views.

PNM displays more convincing arguments for holding that prospective parents may have certain moral responsibilities in relation to PCS. Moreover, it provides a more adequate response to the disability right’s critique: the prevention view is not denied in order to serve the ‘world’ or to create a ‘comparatively better outcome’, but to spare children the burden of being born with a severe (and often lethal) genetic disease. PNM invites us to consider that elevating respect for reproductive autonomy above all other values may not be that obvious with regard to recessive diseases that seriously jeopardize the quality of life of future offspring. In the absence of overriding moral considerations, reproductive autonomy in the sense of a moral right to choose as one pleases may be limited by individual-ethical concerns related to the suffering of future children. PNM thus suggests that the preventive options created by new genomic testing possibilities are not morally indifferent, but bring along new parental responsibilities. Instead of ignoring these responsibilities, the screening and counselling process should enable and motivate prospective parents to live up to them.

It has been suggested that it will only be a matter of time before (preconception) EUCS becomes widely available. How should this new screening proposition be offered to prospective parents if we take into consideration the reproductive responsibilities ensuing from PNM? Taking account of PNM1, preconception EUCS should not be presented as a substitute for, but as an addition to PCS for high-risk couples. According to PNM1, couples with a known increased risk of passing on one of the worst recessive diseases would have a moral duty to take preventive measures. This duty, however, does not extend to milder diseases included in the EUCS panel, nor to severe diseases for which there is no increased risk. If preconception EUCS were to replace PCS for high-risk couples, it would become less transparent for these couples to see what their moral responsibilities are with regard to carrier screening. A preconception EUCS programme taking account of the moral duties entailed in PNM2 would lead to a screening offer consisting of a prevention-aimed panel covering the worst genetic diseases and an autonomy-aimed panel for comparatively milder diseases. Following PNM2, all couples who wish to have children would have a moral duty to undergo PCS for the first panel and, in the case of a positive test result, avoid the conception of an affected child. With regard to the second panel, couples should feel ‘free to make [choices] on the basis of their own values in the light of their own conceptions of what it means for a life to go well’. If the launching of a prevention-aimed PCS programme based on PNM2 is considered proportionate, this would not only bring moral duties for prospective parents, but also for reproductive health counsellors and governmental institutions. These responsibilities will be discussed in a different paper (forthcoming).

57Savulescu & Kahane, op. cit. note 51, p. 277.
58Cf. Holm, S., & Bennet, R. (2014). The proper scope of the principle of procreative beneficence revisited. Monash Bioethics Review, 32(1-2), 22–32.
59Herissone-Kelly, P. (2006). Procreative beneficence and the prospective parent. Journal of Medical Ethics, 32(3), 166–169.
60Savulescu & Kahane, op. cit. note 51, p. 277.
61Holm & Bennet, op. cit. note 58.
62Edwards et al., op. cit. note 16.
63Parker, M. (2007). The best possible child. Journal of Medical Ethics, 33(5), 279–283.
CONCLUSION

The presentation of EUCS as a proposition that first and foremost seeks to enhance the reproductive autonomy of prospective parents seems to be embraced without much reflection. In the near future, couples as well as reproductive health counsellors will have to deal with questions related to EUCS, so we have sought to provide an ethically sustainable account of its aims. We have shown that it should not be taken for granted that all forms of carrier screening should prioritize autonomy over prevention, notably if such screening is offered prior to pregnancy. At the same time, however, we have to be cautious in adopting the prevention paradigm. Even if, in principle, prospective parents may have certain moral responsibilities in relation to PCS, these responsibilities may be overridden by competing moral considerations, such as the emotional and moral burden of taking preventive measures.

We have argued that an appeal to parental responsibilities cannot justify the implementation of a prevention-aimed preconception EUCS programme covering a wide array of – severe as well as mild – recessive conditions. However, it may lay the foundation of a more limited prevention-aimed PCS panel including only the worst recessive disorders. Such a limited screening panel may be offered to couples with an a priori increased carrier risk for the disorders included in the panel, or to all couples who wish to have children. Offering PCS for the worst recessive conditions under the banner of ‘prevention’ rather than ‘autonomy’ reflects the message that the preventive options created by new genomic testing possibilities are not morally indifferent. In this way, the screening offer may stimulate prospective parents to reflect on what their moral responsibilities are with regard to PCS.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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