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ORIGINAL ARTICLE

Preconception care and genetic risk: ethical issues

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Abstract Preconception care to address genetic risks in reproduction may be offered either individually to couples with a known or suspected increased risk of having a child with a genetic disorder, or systematically to couples or individuals of reproductive age. The identification of couples at risk of transmitting a (serious) genetic disorder allows those couples to refrain from having children or to adapt their reproductive plans (using prenatal or preimplantation diagnosis, donor gametes, or adoption). Ethical issues concern the possible objectives of providing these options through preconception genetic counseling or screening, objections to abortion and embryo-selection, concerns about eugenics and medicalization, and issues arising in the professional–client relationship and/or in the light of the normative framework for population screening. Although enhancing reproductive autonomy rather than prevention should be regarded as the primary aim of preconception care for genetic risks, directive counseling may well be acceptable in exceptional cases, and prevention in the sense of avoiding serious suffering may be an appropriate objective of specific community-based preconception screening programmes. The seemingly unavoidable prospect of comprehensive preconception screening raises further ethical issues.

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Introduction

Preconception care aims to provide prospective parents information and support with regard to preconception measures that are conducive to a healthy pregnancy-outcome for mother and child (Health Council of the Netherlands 2007; Atrash et al. 2008). Experience with preconception care as a systematic approach to promoting reproductive health is still limited, as is ethical thinking about conditions and implications. Preconception care then is a practice in the making, still looking for its own identity (Delvoye et al. 2009).

This article gives an overview of ethical issues related to offering preconception care to address genetic risks in reproduction. When targeted to couples with a known or suspected increased risk of having a child with a genetic disorder, genetic preconception care fits within the tradition of individual genetic testing and counseling. It provides counselees with a wider range of reproductive options than they would otherwise have had (Solomon et al. 2008). On the basis of their genetic risk-profile and in the light of their personal weighing of relevant considerations, they may decide to 1) have a child while accepting the risk, 2) reproduce with the use of donor gametes, 3) refrain from having children genetically related to at least one of the partners, 4) establish a pregnancy and then use prenatal diagnosis (PD) with the possibility of having a selective abortion, or 5) conceive through in vitro fertilization (IVF) and use preimplantation genetic diagnosis (PGD) with the hope of being able to select a non-affected embryo.

When however offered to a whole population of reproductive age, genetic preconception care seeks primarily to identify couples or individuals with an increased risk of transmitting a genetic disorder. The basic format is taking an extensive family history as part of general preconception consultation (Health Council of the Netherlands 2007). In most cases, this will not reveal a high risk of transmitting a serious autosomal recessive disease, such as cystic fibrosis (CF) or hemoglobinopathies. Indeed, due to the recessive inheritance pattern, affected children tend to be born to healthy and unsuspecting parents, even if the diseases in question may constitute a serious reproductive health problem in specific populations or communities where they are more frequent. The systematic and uninvited offer of testing for carrier status of such diseases may therefore become an important instrument of genetic preconception care (Solomon et al. 2008). Experience with this approach also includes X-linked recessive diseases, notably Fragile X syndrome (FXS) (Musci and Moyer 2010). In the two main sections of this paper we review the ethics both of individual preconception genetic counseling and of systematically offering preconception carrier screening (PCS) to couples or individuals of reproductive age, either targeting specific diseases or using expanded (potentially even genome wide) test-panels.

Ethics of individual preconception genetic counseling

Ethical issues of preconception counseling of individual couples with a known or suspected increased genetic risk include the objectives of genetic counseling, the ethics of abortion and embryo-selection, and issues arising with regard to the professional–client relationship.

Objectives of individual preconception genetic counseling

There are two different views of the aim of preconception care for individual couples with increased genetic risk: prevention and autonomy (Buchanan et al. 2000; De Wert 1999). According to what we will refer to as the 'prevention view', the provision of information and counseling (and testing) to these couples aims at preventing the birth of children with (severe) genetic disorders. This may be motivated by an ethical (prevention of suffering) or a health economic (reducing societal costs) concern, or by both. Both versions of the prevention view fit in with the notion of preconception care as a general means for promoting healthy pregnancy outcomes for mother and child.

The dominant view with regard to reproductive counseling in clinical genetics, however, is that this practice serves the quite different end of enhancing opportunities for meaningful reproductive choice ('autonomy view') (De Wert and De Wachter 1990). The ethical argument for this position is that reproductive decisions are and should remain personal and that this is difficult to reconcile with treating them as means to achieving societal goals. This view holds that under the prevention perspective, there is a risk that prospective parents will be expected to make the 'right' decisions and that it will become normal and logical to hold them accountable for the consequences if they do not. This is especially regarded as problematic where abortion decisions are concerned. The only way to avoid pressure on pregnant women and their partners to test for fetal abnormalities and to terminate affected pregnancies would be to clearly distinguish between enhancing reproductive autonomy as the aim of genetic counseling on the one hand and avoiding the birth of affected children as a possible consequence on the other. Of course, this notion of enhancing reproductive autonomy must be qualified as focused on decision making with regard to (serious) health problems in prospective children (Health Council of the Netherlands 2001). Without this qualification, the question might arise why prenatal testing should not also be offered for sex selection, or even to enable deaf parents to abort a hearing child.

Moral acceptability of embryo-selection and abortion

As genetic counseling may lead to discarding embryos (after IVF/PGD) and to aborting foetuses (after PD), a central issue concerns the moral acceptability of these options. This debate turns on the 'moral status' of human embryos and foetuses (De Wert 1999; Knoppers et al. 2009). On one end of the range of possible positions, there is the view that they are to be regarded as persons with a corresponding near absolute right to protection—a view which is difficult to reconcile with societal acceptance of e.g. intra-uterine devices. On the other end, some argue that embryos and foetuses are just tissues and cells with no moral status whatsoever. In between these more extreme positions, most argue that human embryos and foetuses have a real, but *relatively low* moral status, which can be overridden by other morally relevant considerations, including the wish to avoid transmitting a (serious) genetic disorder to one's children (Health Council of the Netherlands 2001; Knoppers et al. 2006).

For those who accept the idea of 'gradualism'—meaning that the status of the embryo and foetus increases with its development—embryo-selection will be morally preferable over abortion, and earlier abortion over later (De Wert 2009; Knoppers et al. 2006). In this light, early PD by means of non-invasive testing in maternal blood may be seen as a morally important new development (De Jong et al. 2010). Moreover, many would find abortion even for 'medical reasons' only acceptable up to foetal viability or to some other limit related to the notion of increasing moral status (Boonin 2003). These lines may or may not correspond with legal abortion-limits as drawn in different jurisdictions.

Responsible practice: informed decision making and the limits of non-directivity

In the context of reproductive counseling, the option of genetic testing of the counselee(s) (and/or close relatives) will often be proposed in order to obtain a more accurate view of the transmission risk. Such testing requires the voluntary and informed consent of the person to be tested (Knoppers et al. 2006). This requires professionals to provide adequate (balanced and sufficient) pre-test information about the aim and nature of the test, the test procedure, and the meaning and implications of possible outcomes. Informed consent is not an end in itself, but a means to enable autonomous decision making. This is more strongly emphasized in the notion of 'informed choice': the person to whom testing is offered must be helped to make his or her own weighing of the pros and cons, also taking account of possible psychosocial implications, and making a fit with his or her personal values and beliefs (Marteau et al. 2001).

This account of informed decision making is closely related to the ideal of professional non-directivity (De Wert 1999). In the context of reproductive counseling, this requires professionals to create a climate in which those 'at risk' can make their own decisions, not just about testing, but also with regard to choosing reproductive options. Directive counseling is generally regarded as problematic in this context, given that people may have very different views about what reproductive risks are acceptable (Wertz and Knoppers 2002).

Still, there are situations where advising counselees to avoid reproductive risks may well be appropriate. One should think here of cases where both the chances of having an affected child and the level of suffering and harm for those having the disease are high. An example would be a couple with a child-wish where the woman is a known carrier of Duchenne muscular dystrophy (DMD). Given the X-linked inheritance pattern, this means that their risk of having a child with DMD is 25%: if the child is a boy, one in two will have this very serious disease that strikes already at an early age. What if this couple makes clear that because of their views about abortion and embryo-selection, they would not want to have prenatal or preimplantation genetic diagnosis? Would advising them not to take the risk of having a child with DMD (but opt for IVF with donor oocytes, try to have a child through adoption, or refrain from having children) be an instance of disrespecting the counselees' right to reproductive autonomy? We do not agree. We think that thus advising the couple may in fact be understood as taking them seriously as autonomous and therefore responsible agents in the parental role they want to assume. When taking a directive stance in such situations, counselors should of course limit their efforts to rational (non-coercive) persuasion.

Another situation where directivity may be appropriate emerges when due to a fertility problem, a couple at a high risk of transmitting a serious disease (such as DMD) can only reproduce through medically assisted reproduction. Given their direct and causal involvement in the realization of the parental project, fertility doctors have the professional responsibility to refrain from medically assisted reproduction in case of a high risk of serious harm to the child (ESHRE 2007). It may therefore be morally appropriate to offer genetic testing to applicants at risk of having an affected child as a *condition* for access to medically assisted reproduction (ESHRE 2011). Here, appropriate directivity may even go beyond persuasive advice and take the form of a 'coercive offer'.

We have suggested that directivity may be appropriate in cases where reproduction would entail a high risk of serious harm. Inevitably, there will be different opinions about where the line between risks that are and are not in this category must be drawn (Wertz and Knoppers 2002). Acknowledgement of these differences does not stand in the way of maintaining that there are moral limits to the ideal of non-directivity. What it does entail, however, is that there is a grey area in which the justification for directive counseling is far less obvious than in the more extreme cases that would not lead to much disagreement.

Responsible practice: confidentiality and the interests of relatives

A further situation where non-directivity cannot be guiding may emerge when genetic counseling or testing has revealed that close-relatives of the proband are at a risk of serious, avoidable harm. In such cases, the counselor should urge the proband to inform those relatives (or to take steps in order to have them informed by somebody else). But what if the proband refuses and is also not willing to discharge the professional of her duties of confidentiality? It has been suggested that not the individual, but the family should be taken as the 'unit of confidentiality' (Lucassen 2007). However, this 'solution' is rejected in most of the relevant ethical and legal literature (Clarke 2007; Knoppers 2002; Offit et al. 2004). The principle remains that only when facing a conflict of duties, professionals may inform a patient's or client's relatives without his or her consent (Lacroix et al. 2008). This requires a delicate weighing of relevant considerations (President's Commission 1983). Criteria include the following: all efforts to obtain consent have failed; the situation must amount to a case of conscience; not informing the relatives would probably lead to serious harm or suffering; and the inroad upon the patient's or client's privacy is kept as small as possible.

Cascade screening

A final issue regards the systematic offering of genetic testing to relatives of the proband. Such 'cascade screening'

may be an effective strategy to identify persons at risk both of having and transmitting genetic disorders that because of their autosomal dominant inheritance pattern are highly frequent in affected families (Morris 2004). This includes diseases such as hypercholesterolemia (Newson and Humphries 2005) and hereditary cardiac arrythmias (Hofman et al. 2010). Cascade screening has also been considered for Fragile X syndrome (Morris 2004; De Jong and De Wert 2005). In the context of preconception care, cascade screening is intermediate between counseling and testing of individual couples with a known or suspected increased genetic risk (this section) and genetic screening as offered to all those of reproductive age (see next section). Offering cascade screening in affected families has been criticized because of its uninvited nature and the possible invasion that this may entail of the 'right not to know' of individual family members. However, depending on the disease in question and the amount of harm that a timely warning could help to avert, the 'right to know' of family members at risk may well be the morally overriding consideration (De Wert 2005).

Preconception carrier screening

Ethical issues with regard to PCS include preliminary concerns about eugenics, medicalization, and discrimination, the objectives of offering PCS, and issues arising in view of the normative framework for population screening. We will end this section with a brief discussion of the possible future expansion towards comprehensive PCS.

Eugenics, medicalization, discrimination?

PCS is more controversial than individual genetic counseling. Critics object for different but related reasons to the fact that in this approach genetic preconception care is meant to serve the reproductive health of the population as a whole. Why would that be problematic? Some are concerned about a supposed resurgence of 'eugenics' (Scully 2008); others speak of 'medicalization' (Verweij 1999). However, as those terms have many different meanings, it seems more fruitful to ask what scenarios people actually fear and to assess the likelihood of those scenarios (Bouffard et al. 2009; Paul 1994). For instance, people may think of government restrictions of reproductive freedom, as in Nazi Germany. That scenario, however, is quite implausible, at least in Western democratic societies. Fears about societal pressure to participate in screening or to choose specific reproductive options seem more realistic. But that should be taken as a reason for developing and implementing an appropriate system of safeguards, not as a ground for categorically opposing this form of preconception care (De Wert and De Wachter 1990). We will return to this when discussing the normative framework for PCS.

Another issue is the 'disability rights' critique. The so-called 'expressivist argument' states that taking measures to avoid the birth of a child with a specific disorder or disability expresses a discriminatory view regarding the worth of the life of those living with such conditions (Parens and Asch 2000). If taken as a claim about parental motives this cannot be maintained. Prospective parents may want to protect their child from harm, or they may feel that they would not be able to be good parents for a (severely) disabled child. None of these motives expresses a discriminatory attitude towards disabled persons (Knoppers et al. 2006). But the argument may also be directed against the systematic offer of reproductive testing for specific diseases. Does this not send the message that persons with the diseases screened for are a burden to society and would better not be born (Scully 2008)? There is certainly a risk that PCS may lead to reinforcing existing tendencies of stigmatization and discrimination (Wilfond and Fost 1990). Here again, much depends on how the programme is presented and conducted in practice.

Objectives of offering PCS

As a form of reproductive screening, it would seem that PCS is better compared with autonomy-directed prenatal screening for Down syndrome and other foetal anomalies, than with prevention-directed screening for, eg, breast-cancer (Dondorp et al. 2010). Indeed, the arguments behind the strong emphasis on reproductive autonomy in the clinical genetics tradition seem equally relevant when PCS is concerned. However, there may be some room for differentiation between PCS as a top-down initiative from the health care system (as in the case of the recently introduced obligatory offer of PCS for CF in the USA; ACOG 2011) and community-based initiatives targeting high profile genetic risks for serious diseases within that specific community or population. Whereas reduced birth rates of affected children should not be regarded as the measure of success of the former type of programmes, doing so may seem less problematic for programmes of the latter kind (Laberge et al. 2010). The difference being that in programmes set up in answer to a need for prevention as self-defined by a community in which many families are struck by a high burden of disease, most participants will actively support the aim of bringing down the birth-prevalence of the disease, whereas this is less obvious in top-down programmes aimed at populations rather than communities. With regard to this tentative distinction we make the following comments. Firstly, the material (genetic risk and burden of the disease) and procedural (community involvement) criteria would require further exploration. Clearly, a high population frequency of an untreatable, debilitating and lethal disease such

as Tay Sachs Disease (TSD) would amount to a high risk of serious harm. And it would seem that the same can also be said of β thalassemia in regions and countries where that disease is highly frequent, even though it is amenable to some form of treatment. But for diseases that are less serious or highly variable or well treatable, enabling autonomous choices rather than prevention should be the objective of PCS. Where the line would have to be drawn is a matter for further debate, involving the participation of the relevant communities themselves. The procedural criterion of bottom-up community involvement and support would also require more precise determination. Secondly, although this brings in the prevention view, it is prevention as primarily motivated by the community's concern about the suffering of its children and families, rather than by health economic considerations. Finally, to say that prevention may under conditions be a morally legitimate objective of community-based PCS is not to deny that pressure on individuals or couples is a concern also in those contexts. Especially in socially tight communities, pressure to participate in prevention-aimed PCS is far from imaginable, and safeguards are needed to avoid this (see next subsection).

Normative framework

For the normative assessment of population screening programmes, a general framework of criteria has been developed (Dondorp et al. 2010; Health Council of the Netherlands 1994). At the core of this framework, there is a requirement of proportionality: there must be a proven positive balance of benefits over harms for those participating. Whether this requirement is met can only be determined on the basis of scientific evidence regarding many separate aspects including the natural history of the disease, how screening may provide meaningful options for changing an otherwise dreadful outcome, and possible psychosocial implications. Further criteria refer to test characteristics, quality issues, cost-effectiveness etc. It is also stressed that participation must be voluntary and based on informed choice.

There is strong consensus that some PCS programmes meet these criteria, whereas some other programmes do not, or less clearly. For instance, with regard to PCS for Fragile-X syndrome (FXS) there are concerns that may affect overall proportionality (De Jong and De Wert 2002; Musci and Moyer 2010). First, it is not always clear as to whether women carry an unstable allele which may cause FXS in offspring—think, for example, of 'intermediate' alleles in the grey zone. Such findings change the nature of carrier screening for FXS into a form of risk assessment screening, potentially inducing higher levels of anxiety and complicating decision making. Second, unlike other carrier screening programmes, screening for fragile-X carriers will identify individuals who themselves are at risk for adult-onset disorders, more in particular premature ovarian failure (POF) and fragile-X-associated tremor and ataxia syndrome (FXTAS). And third, phenotype prediction in female foetuses with a full mutation is difficult, if not impossible. Cascade screening may be a more acceptable approach to identify female carriers of FXS (De Jong and De Wert 2002; De Wert 2005). An important advantage being that one starts from (a patient with) a disease-causing allele, allowing for more straightforward genetic counseling.

With regard to PCS for CF, the apparent lack of international consensus is reflected in a recent European consensus document that only provides a template for further debate (Castellani et al. 2010). The reasons behind this include the fact that due to the large number of CFTR mutations, CF carrier tests have a less than perfect sensitivity and also that for many mutations the genotype–phenotype correlation is weak. However, in a Dutch study, it was found that PCS for CF would in principle fulfil the requirements of the normative framework (Henneman et al. 2002).

Screening in the context of reproduction is especially sensitive as it may affect decision making with regard to having or avoiding to have children with a disease or disability. It is far from imaginable that as a result of offering such screening, these choices will come under pressure as to what professionals or society would like to see happen. That is indeed the concern behind the charges of eugenics and medicalization briefly discussed in the beginning of this section. As suggested, the only way to answer this is through safeguards that protect reproductive freedom. Some of those safeguards will need to be integrated in the set-up of the programme. These include adequate provisions for ensuring voluntary, well-informed decision making regarding participation in PCS, the availability of non-directive counseling (within the limits earlier referred to), and a systematic evaluation aimed at identifying and removing elements of unjustified directivity. Other safeguards will have to be of a societal nature, including the continued availability and funding of proper health care services for children born with the diseases targeted in PCS, also when their parents had the option to choose to avoid their birth (Human Genetics Commission 2011).

Modes of offering carrier screening

Carrier screening may be offered either in pregnancy or preconceptionally, and if preconceptionally, either to couples with possible reproductive plans or to all individuals of (pre-)reproductive age. Which of these approaches is more in line with the proportionality requirement of the normative framework will to a large extent also depend on whether prevention or autonomy is taken as the overarching objective.

In terms of enabling reproductive choices, carrier screening in pregnancy is clearly suboptimal. Prenatal carrier

screening leaves couples found to be at a 1:4 risk of having a child with a serious disease no other options than either accept that risk or opt for PD and a possible abortion. Moreover, it forces them to start thinking about this under time pressure in what is already an emotionally charged period. Organizationally, however, the preconception approach is more challenging. Pregnant women and their partners are easier to find than couples with possible reproductive plans. As proposed by the Health Council of the Netherlands, the introduction of a general preconception consultation might help to create a context for the offer of PCS (Health Council of the Netherlands 2007). Since not all couples will be reached preconceptionally, a combination of both approaches may be optimal: offering prenatal carrier screening as a back-up to couples who for whatever reason did not participate in PCS.

PCS is usually offered to couples rather than to non-committed individuals. It is couples who have more imminent reproductive plans, and it is as couples that they may be found to be at a high risk of having a child with an autosomal recessive disease. But couples can be regarded and approached in different ways: either as single units or as unions of two separate individuals (Castellani et al. 2010). The single unit approach aims at informing the partners jointly about whether or not they are a carrier couple. In case of a discordant outcome, individual carrier status is not always reported. This deprives a possible carrier of the option of informing his or her relatives and of using this information in a future relation with another partner (Modra et al. 2010). Withholding this information is legally questionable and at odds with the objective of enhancing reproductive autonomy. Nor does it seem that being identified as a carrier has a more than transient psychological impact on well-informed testees (Lakeman et al. 2008).

The alternative approach of regarding the couple as a union of two individuals entails simultaneous testing of both partners and providing information about all individual outcomes. Drawbacks are that this doubles the costs of testing and leads to the identification of twice-as many discordant couples. In PCS for CF, this outcome requires careful counseling in the light of the fact that the risk for these couples has increased as a result of testing (Ten Kate et al. 1996).

PCS is sometimes also offered in non-clinical settings (workplace, school) to individual adults or to adolescents, as candidate participants may thus be more easily and effectively reached. It has been argued that from an ethical point of view, this approach has the benefit of ensuring equity of access (Modra et al. 2010). Offering PCS to adolescents means educating their parents as well, leading to an increased awareness in the population as a whole.

One concern with addressing individuals is that it might lead to stigmatization and lack of self-esteem of those found to be carriers within the community. That this is not unimaginable has been illustrated in a recent analysis of the orthodox Jewish Dor Yeshorim PCS programme (Raz and Vizner 2008). However, much seems to depend on how the screening is offered and what information is given (Modra et al. 2010). Proper education about the meaning of being a carrier is of course crucial. This should also include the fact that in terms of carrier status for recessive disease, we are indeed all ‘fellow mutants’. Clearly, society needs to be educated about this as well: identification of carriers and patients led to the erroneous rejection of carriers by American insurance companies in the early 1970s.

Another concern regards the voluntariness of participation, especially when PCS is offered to adolescents (Barlow-Stewart et al. 2003). The UK Human Genetics Commission recently recommended that offering PCS to adolescents may be acceptable under strict conditions protecting their autonomy rights (Human Genetics Commission 2011). Still, one may object that the trade-off between the relevance of testing to the young person (increasing as they grow and come closer to the time that they may wish to start a family) and the ease of population coverage (becoming progressively less complete, or more costly, as the age of the target group increases) is risky in view of less favourable conditions for voluntary and truly informed participation.

Expanding testpanels

Traditionally, PCS regarded one single disease. In the last years, however, there is a tendency of using test panels for several diseases. A recent PCS pilot in Quebec, Canada, is directed at four diseases with a high frequency in the population (1:5) due to a historic founder effect (Charlevoix–Saguenay spastic ataxia; peripheral neuropathy with or without agenesis of corpus callosum; lactic acidosis COX deficiency; and hereditary tyrosinemia type 1) (personal communication Dr. Claude Laberge, Quebec). The best example of expansion of traditional programmes is PCS offered to the Ashkenazi community; originally focused on TSD only, it presently includes up to 16 genetic disorders, an expansion which seems to be strongly supported by the community (Scott et al. 2010). Expanding testpanels with diseases that, although less frequent in the relevant population, are serious and without meaningful treatment options sounds reasonable, provided that genotype–phenotype relations are well understood and good-quality tests are available. However, there is debate about whether expanded panels should also include lower-penetrance mutations, where disease severity is difficult to predict and homozygotes may well remain asymptomatic. An example from the group of 16 diseases just referred to is type 1 Gaucher Disease (GD), which not only has a low-penetrance and variable expression, but for which effective treatment is also available (Zuckerman et al. 2007). It is clear that if PCS is to be offered for such diseases,

the rationale will have to be the provision of autonomous choice rather than the prevention perspective governing traditional PCS in the Ashkenazi community. Mixing the two perspectives in one programme is morally risky as this might send the message that also minor health problems are to be avoided by responsible reproductive decisions (Raz and Vizner 2008).

Driven by technological developments, expansion of PCS seems unavoidable. New techniques, such as the use of DNA chips and next generation sequencing, will allow carrier status to be simultaneously determined for many more recessive conditions than are included in current screening programmes, without significantly increasing the costs. American researchers recently reported to have developed a PCS test for no less than 448 severe recessive childhood diseases (Bell et al. 2011). The question is whether such 'comprehensive' PCS will fulfill the criteria for responsible screening. For each of the separate conditions this will depend on whether the relevant mutations are known, on what is known about the disease and genotype–phenotype correlations, and whether a good quality diagnostic test is available. Introducing carrier screening that would lead to couples making far-reaching reproductive decisions on the basis of test results of which the implications are not yet fully understood is morally unacceptable. Another concern regards the quality of informed consent. The introduction of genome-wide testing questions the feasibility of informed consent as traditionally understood and urges society to consider the acceptability of so-called generic consent, where applicants are only more generally informed about types of possible test outcomes and their implications (Dondorp and De Wert 2010).

Concluding remarks

A core thread of this paper is that there are good moral reasons for regarding the enhancement of reproductive autonomy rather than prevention as the primary objective both of individual preconception genetic counseling and of PCS. Nevertheless, we have argued that there may be room for differentiation in both contexts. In exceptional cases where reproduction entails a high risk of serious harm, individual counseling may well be directive. Similarly, prevention in the sense of avoiding serious suffering may under conditions be a morally acceptable objective of PCS. Prevention in this sense should be distinguished from prevention aimed at cost reduction for the health care system. Where PCS is offered for reasons of cost reduction, reproductive freedom is under threat of being curtailed for purely health economic considerations, possibly leading to pressure to also avoid the birth of children with minor or treatable disorders. In this connection, the prospect of comprehensive PCS is worrisome, because it neither makes an easy fit with the objective of enabling meaningful reproductive choices nor with prevention as aimed at serious suffering. As Clarke and Thirlaway (2011) have recently warned, comprehensive PCS as an instrument of cost-reduction, with targets of near universal compliance also with regard to termination of affected pregnancies, may be regarded as attractive by state healthcare systems 'in countries with young populations, rising expectations and limited resources'. In Western countries, a more subtle scenario seems more likely: broad-scope PCS may be sold to the public under the banner of giving people choices, but without caring much about whether those choices are real and meaningful (Dondorp and De Wert 2010). The best way of challenging these possible scenarios is through investing in the counter scenario of PCS programmes in which the autonomy-objective is allowed to be a practice-shaping force, rather than just a banner or a slogan.

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