Predictive Testing for an Individual at 25% Risk for Huntington's Disease: Present Conundrums, Future Challenges

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Abstract

The potential for predictive medicine to impact upon many aspects of future social life is increasingly discussed in the literature. Against the background of developments in this emerging field, this paper examines a case study of some of the complex predictive testing issues for an individual at 25% risk of Huntington's Disease (HD). Whilst the case study primarily relates to predictive testing for a single-gene, mature onset disorder, all genetic test information, by its very nature, involves inter-generational material which may have simultaneous and direct relevance for multiple family members within a family context. The availability of such testing therefore, can present complicated ethical dilemmas for at-risk individuals who are considering it, because as primary autonomous decision-makers, the testing decision carries significant and possibly competing ethical responsibilities towards both self and significant others. This case study analysis illustrates the complex interplay of competing rights within a family group and some of the moral issues which are raised for the individual who wishes to consider it; it also explores the notion of genetic privacy within this context of family and the fragility of some family members' rights "not to know" their genetic status. The case study is also examined against the background of current clinical service delivery models, with the conclusion that such models, when based upon individual rights and bioethical frameworks, become problematic within this context. Finally, it is argued that there are issues of social justice for at-risk individuals and families in such situations. The broader socio-political and public health imperatives relating to the potential use of predictive test technologies can have significant implications for individuals with known genetic risks such as those described here; these need to be acknowledged and addressed in a socially responsible way.

Introduction

Predictive medicine is an emerging field of medicine which is being generated by technological developments in human genetics. Several hundred "predictive" genetic tests are now available with regard to known disease-causing, or disease-predisposing, mutations (O'Sullivan, Sharman & Short, 1999) and these have the capacity to generate information about individuals' future disease status and/or predispositions to future disease. Within such a context therefore, it is not surprising to note that predictive genetic tests are often depicted in broader philosophical contexts relating to visions about future life and the potential impact of such technologies upon future people, future reproductive practices and future social structures; Richards (2002) for example, describes predictive technology in terms of its relevance to "future bodies" while Annas (1996, cited in Everett

2002) describes DNA as "a coded probabilistic future diary". The potential impact of predictive medicine then is seen by many to be very significant in many aspects of future social and personal life.

It is difficult to generalize discussions about predictive tests however, as there are many different types of disorders which can be tested for in this way, and the implications of test results may vary considerably (Chapman, 2002; Rothstein, 1997). As the name suggests, "predictive tests" generally relate to one's future health or illness; they are generally undertaken by otherwise fit and healthy individuals who have no apparent symptoms of disease at the time of testing but who have reason to believe, perhaps because of a known family history of an inherited condition or disorder, that they, or their pregnancies, are at risk of being affected by a disorder in the future. This differs from diagnostic tests which are typically undertaken to establish or confirm disease in an individual who already has symptoms or some evidence of disease or pathology. In the recent past, predictive tests were mostly discussed within the context of individuals who had risks of serious, often rare, diseases caused by single faulty genes in their families; developments associated with the Human Genome Project and its aftermath however, have extended the potential application of predictive medicine to the broader population with more "mainstream" health conditions such as respiratory or cardiovascular diseases, diabetes or obesity (Petersen & Bunton, 2002; Davison, 1995). Within the latter context, it is envisaged that predictive testing could be used to establish individuals' genetic susceptibilities or predispositions to future illness, and then followed up with preventive pharmaceutical or other prophylactic measures to reduce, minimise or eliminate that individual's predicted future diseases. Given the uniqueness of each individual's genetic profile, such a projected scenario picture could represent the ultimate model of personalized, preventive health care (Petersen and Bunton, 2002; Khoury et al., 2000).

Whilst the potential benefits of predictive medicine may appear evident within this public health context, there are however many ethical, legal and social complexities associated with this technology (Leeder, 1999; Marteau & Richards, 1995). One fundamental issue of importance is that many of the conditions or diseases which can be predicted in an individual are as yet untreatable; as Terrenoire (1992) noted, the development of such technologies "..[has] put modern medicine in the uncomfortable position of being able to foresee future conditions that it cannot treat" (p.79). The primary value of a predictive test in this instance therefore is for its information outcome. Such information can be helpful to individuals and families for a variety of reasons, depending upon the nature of the disorder being tested for. Individuals who are shown to have faulty genes predisposing them to greater risk of some inherited breast or bowel cancers for example, can have ongoing medical surveillance for early detection of disease; others for whom such surveillance is medically irrelevant, such as those at risk for Huntington's Disease (HD) and other mature-onset neurodegenerative diseases, can undertake testing to confirm a future HD disease status, or not, thereby perhaps experiencing greater emotional certainty and accessing information which may be useful for life planning purposes or reproductive decision-making. In all these instances however, concerns have been expressed about the potential "burden of knowledge" for individuals who may have to accommodate knowledge, perhaps for years, about certain, or increased risk of, serious disease in the future (Terrenoire, 1992). While debate about the nature and degree of "certainty" associated with predictive test information occurs in the literature (for example, Davison, 1996), nonetheless the information which emerges from a predictive test will mostly alter or modify, to a significant degree, an individual's understanding of their risk from that which they had prior to testing. Once treatments or prophylactic interventions are available for conditions which can be predicted before the onset of symptoms, ethical issues and concerns associated with this "burden of knowledge" aspect of predictive testing, may be considerably lessened.

Another important feature of genetic test information relevant to this discussion is that is it

"irreversible"; as Evers-Kiebooms and her colleagues (1987) noted "[T]here is no escape after predictive testing: once a person receives the information, there is no way of obliterating the knowledge" (p.275). This is an important issue and requires understanding by those unfamiliar to this context. The decision to undertake a predictive genetic test for a serious, untreatable disease is usually a major decision in an individual's life, because of the potentially profound personal and life implications associated with the test outcome. Many accounts have been written about individuals' experiences of such testing within the Huntington's Disease context and of the adjustment and "recovery" required after such experiences (Cox, 1999; Taswell & Sholtes, 1999; Wilkie, 1995). Thus, it is extremely difficult for either a tested individual or for others to whom his or her test result is disclosed, to deny or mentally dispense with the information and/or its implications. This is not only a relevant issue within personal or family contexts, but increasingly within a range of broader social contexts, where the right to an individual's predictive test information is contested by third parties such as employers, insurers or financial lenders, who may indeed require its disclosure. The emerging phenomenon of genetic discrimination, that is, discrimination which is based solely upon an individual's genetic profile, has been variously described in the literature (for example, Barlow-Stewart & Keays, 2001; Taylor, 1998; Billings et al., 1992). The concept of "genetic privacy" becomes highly relevant in this context, underpinned by an assumption that genetic information is a special type of property, the ownership of which can be contested (Everett, 2002; Leeder, 1999; Rothstein, 1997). Thus, the "irreversibility" of genetic test information is a salient issue here and one which has often been implicated in discussions about why individuals might not engage with predictive test technologies within social or legal contexts where their rights to privacy cannot necessarily be assured (Rothstein, 1997; Evers-Kiebooms et al., 2000).

A final and related characteristic of relevance when discussing important aspects of predictive genetic test information concerns the inherently shared and generational nature of information about an individual's inheritance or genetic makeup. Within the context of single gene disorders such as Huntington's Disease, a predictive test result can have relevance far beyond the testing individual alone, as it may ultimately contain "first-degree" information about other biologically-related individuals such as parents, grandparents and siblings. Thus, the concept of genetic privacy can also have relevance in this potentially intimate and complex family context. While genetic privacy has been widely discussed in contexts relating to contested rights between testing individuals and broader third party groups such as insurers or employers, it is less discussed within the context of family and kin relationships. This is one of the issues explored in this paper which, through a case study analysis of test decision-making relating to Huntington's Disease, examines competing rights and moral concerns of family members regarding their shared genetic information. While as Everett (2002:236) notes, it may be "tempting to believe that the findings of predictive genetic tests will be relatively easily assimilated into family life", the potential impact of genetic test information within the family context can be a very complex issue. The implications of such complexities for service providers and the broader community will also be discussed in this exploratory paper.

Huntington's Disease and Predictive Genetic Testing

Huntington's Disease is caused entirely by the inheritance of a single abnormal HD gene from either parent and is thus referred to as a "single gene disorder"[1] (Harper, 1996). It is a neurological, degenerative disease and, as symptoms typically emerge in the third or fourth decades of life, is also known as a "mature-onset" condition. Such symptoms once they do appear, can include involuntary movements in the body as well as intellectual and emotional impairments. HD is currently incurable and for those affected by the condition, death typically occurs on average fifteen to twenty years after diagnosis. All male and female children of a person affected by HD have a 50% risk of developing the

disease if they reach the age of onset and their offspring in turn are said to be at 25% risk; such individuals are thus often described in general terms as "being at risk". While HD is regarded as a mature-onset condition, the exact age at which the disease process may begin is unknown for any one individual; at-risk individuals therefore, can carry worry and uncertainty, possibly for years, about whether or not they will develop HD in the future and if so, at what point in time. "Being at risk" can therefore be accompanied by many stresses over a long period, particularly as at-risk individuals approach the age at which onset of HD has typically occurred in their family; it has been variously likened to living in a state of impending threat or to living with a 'time bomb' (Tyler, 1996; Wexler, 1979). By the forties or fifties, when symptoms of HD typically begin to develop in an individual, s/he often has significant responsibilities relating to family life, career and financial commitments; the onset of a serious, untreatable and degenerative disease at this stage of life can therefore have widespread ramifications for the individual and multiple others in the family. "Symptom-watching" is commonly reported in HD families, as people become hyper-vigilant in scanning themselves and/or each other for possible emerging symptoms of HD such as clumsiness, restlessness or faltering memory (Harper, 1996).

The isolation in 1993 of the abnormal HD gene (Huntington Disease Collaborative Research Group, 1993) and the subsequent development of a predictive DNA genetic test for HD, were immensely welcome and significant events for at-risk individuals and families, who generally saw it as an important scientific breakthrough and the basis for renewed hope for future treatment or cure (International Huntington Disease Association, 2002). Those who undertook a predictive test and were shown not to carry the faulty HD gene (i.e. those testing gene-negative) could potentially be spared many years of stress and uncertainty and could undertake key life decisions knowing that their future would be HD-free; further, all offspring of such individuals were similarly assured. For individuals testing gene-positive for HD there were also some benefits, in spite of the challenges that such a test result could bring; the former included emotional relief associated with certainty of knowledge about their HD status and the opportunity to plan and prepare for the future, live life strategically and in an informed way, thereby potentially enhancing their quality of life.

It is not only the testing individual who is affected by his or her test result however, as numerous others such as parents, siblings and offspring share common genetic bonds and therefore may be directly implicated by the test result of one family member. Thus, genetic test information may simultaneously encapsulate "first degree" information—that is, information directly relating to the actual HD status of another person—about numerous biologically related individuals. Further, the availability of predictive testing allows for individuals to be tested out of "logical" generational sequence, as illustrated in the case study presented in this paper; thus an adult individual, if autonomous and freely-consenting, can request testing independently of his/her parent whose HD status may not yet be known but potentially revealed through the offspring's test. The following case study explores and discusses some of the ethical complexities which may be generated for family members in such a situation.

Beverly: A case study

Beverly is a 22 year-old woman whose family has a history of Huntington's Disease. Beverly's grandfather had HD and her 45 year old mother Jean, while at risk for the condition, is as yet uncertain whether or not she has inherited the faulty HD gene from her father. Jean's risk therefore is a 50% one, because she doesn't as yet know her status, while Beverly is said to be at 25% risk. Beverly has been in a secure and happy partnership with John for two years however, and they are now contemplating marriage. Beverly wishes to be tested for HD as she believes it is her responsibility to find out; given that the test is freely available, she wants to build her relationship with John upon "an honest foundation" and believes it is unfair to him and their future relationship, not to be tested. At a

personal level, Beverly also feels she "needs to know" whether or not she has the HD gene so that she can move forward with some clarity about her HD future, and not have to wait for years to find out. Both Beverly and John have also discussed the value of genetic test information in making future life decisions such as whether or not to have a family, the size of such a family if it is decided upon, as well as career and other choices.

In addition to the difficulty of deciding whether or not she, and John, can deal with knowing she might carry the HD gene, Beverly however has additional things to think about when considering her testing decision. Most importantly, because it is unclear as yet whether her mother Jean has inherited the HD gene, Beverly knows is she is found to be gene-positive for HD, so too must her mother (that is, if Beverly is found to have the HD gene, given their family history, it would have had to have come from her mother). At approximately 55 years, the pattern of onset in their family is later than usual; Jean is only 45 years old, has no symptoms of HD and does not want to be tested. Beverly clearly recalls discussions with Jean describing how she (Jean) believed she would not easily cope with a gene-positive test result and feared "dropping her bundle". Beverly also remembers Jean's traumatic stories about her grandfather in his final stage of the disease and knows that Jean's early life was characterized by having many relatives affected by HD, some even institutionalised in psychiatric facilities. Beverly understands therefore that Jean's approach to her risk for HD has simply been to "to live life just one day at a time" and she would wholeheartedly wish to respect her mother's choice in this regard. Furthermore, as well as concerns about Jean, Beverly also has three married siblings, two with five young children between them and the third expecting her first child; all of these siblings have elected, for various reasons, not to have been tested to this point in time.[2] If Beverly proceeds with testing and tests positive for HD, not only would this reveal that her mother too was gene-positive, but her siblings' risks would be regarded as having increased to 50%.

Beverly's decision therefore about whether or not to embark upon predictive testing, in itself a significant and complicated decision, carries additional complexity because her test result has such potentially profound implications for others in her family who have previously elected not to be tested. For Jean in particular, any right she has "not to know" her gene status for HD would be automatically rendered "null and void" if Beverly tests positive for HD;[3] further, Beverly is concerned that such information may place her mother at risk of future psychological or emotional harm. From her own perspective however, Beverly feels a moral responsibility to undertake testing, for her own future well-being as well as her perceived obligations to her future husband and the important life decisions they have yet to make together.

Moral dimensions of Beverly's test decision

Beverly is thus confronting a decision which involves complex moral dimensions: each decisional option that she has, to proceed with testing, or to refrain from proceeding with testing, is accompanied by significant benefits and costs for herself personally, for her prospective partner John and their possible future children, and also for her mother, her siblings and their respective families, about whom she cares greatly. Further, each of these choices has irrevocable consequences: once undertaken, Beverly's genetic test information or its implications cannot be rescinded, forgotten or denied.[4] To proceed with testing and receive a gene-positive result would carry significant implications for her and these multiple others, in particular her mother Jean, who would simultaneously receive first-degree information about herself and her HD status; as well as her own adjustment to such an outcome, Beverly may experience considerable guilt and self-censure, as well as possible censure from other family members, especially if there were adverse consequences for her mother. Refraining from testing on the other hand is not necessarily a simpler alternative, particularly if Beverly feels she needs, or has a moral responsibility, to find out about her HD gene status. If

Beverly is later shown to have the HD gene, perhaps after electing to have children who would then also have a real risk of developing HD, she may still experience guilt and self-censure, as well as censure from others, knowing that the test had been readily available and she had failed to take advantage of it.

The broader context: the clinical genetic setting

Beverly's dilemma can be partially understood by examining the context within which clinical genetic services are currently located and delivered in Australia. Within this context, priority is afforded to the bioethical principle of respect for autonomy: if Beverly voluntarily presents for a predictive test and can competently give informed consent, she will be deemed entitled to undertake such testing. In this scenario, Beverly's right "to know" her genetic status for HD will be upheld and her rights in this context would be legally supported (Skene, 1998). The International Guidelines for Predictive Testing (International Huntington's Disease Association and World Federation of Neurology, 1994), in theory also prioritises Beverly's right to know her genetic status for HD, on the basis that such information can be used to inform other moral decisions she may wish to make. Jean's right "not to know" her HD status on the other hand, is not able to be accommodated within this scenario, unless the whole family agrees to engage with the clinical service and work towards some negotiated resolution of their competing rights (Skene, 1998). If Jean does not agree to such a proposal however, there is no mechanism within the current clinical genetics service context for activating her autonomous choice "not to know": she is not an identified "client" or "patient" within the clinical care system and remains peripheral and technically "invisible", both in terms of her particular needs or subsequent experiences. Jean's right to genetic privacy in this instance therefore, cannot be sustained, in spite of her desire to do so. This also applies to Beverly's siblings, their spouses and children whose lives may be significantly impacted upon by a gene-positive test result for Beverly but who cannot be identified priorities within such a clinical service delivery model. Whilst clinicians and genetic counsellors are generally very sensitive to these complexities in clinical practice,[5] and would actively seek to discuss them and consider possible options at length with Beverly and others if possible,[6] it is nonetheless apparent that Jean's right "not to know" her genetic status for HD in this instance will be automatically over-ridden if Beverly initiates a predictive test and tests positive. This reflects an inherent contradiction in this framework, because theoretically and in any other circumstance, Jean's autonomous right "not to know" her genetic status would be staunchly defended (for example, under the same International Guidelines for Predictive Testing as mentioned above).

Similar cases have been noted in other literature, for example, where one identical twin seeks testing and the other not (Huggins et al., 1996), as well as where a pregnant woman seeks prenatal testing without the knowledge of the fetus' at-risk father (Tassiker et al., 2002). Interestingly, in the accompanying analyses of these two scenarios, clinicians favour the option of not testing the requesting individual, citing beneficence and concern about harming the non-requesting individual; this is in contrast to the analysis given which is based upon bioethical or legal tenets, and which supports testing the requesting individual out of respect for his/her autonomy (Gert, 1996; Skene, 1998; Tassiker et al., 2002). It is important to note that while the professional practice of clinical genetics or genetic counseling is often critiqued within this context (for example, Petersen and Bunton, 2002), clinicians are often acutely aware of the inherent constraints within the bioethical and legal frameworks underpinning the delivery of their services and they often act as concerned advocates for those whose rights may be threatened within such a system.

The cases described above however, demonstrate that the unique complexity of shared genetic information, combined with a clinical system underpinned by discourses reflecting individualised rights and bioethical principles supporting such rights, can generate a

situation in which one family member's right to know, and another's not to, become simultaneously confrontational. While the current clinical resolution of this contestation will occur through reference to the bioethical principle of autonomy, it can also be argued however, that such a resolution is sanctioned by social values about which individual's choice is the most justified: Beverly's right for example, could be seen to be morally and socially preferable as a rational and "responsible" option for herself, her partner and her future children. Jean's right to ignorance on the other hand, could be seen to implicitly reflect "self interest" rather than altruism, in spite of the fact that she may have legitimate fears of psychological and social vulnerability and harm as a result of having gene-positive test information. It is also important to note that Jean's motivation not to undertake testing is shared by the majority of individuals at risk for HD: to date, only 10-20% of all individuals at risk for HD have elected to undertake testing, with a wide range of explanations cited, including the lack of treatment for HD, ideological reasons against testing, fear of the psychological impact of a gene-positive test and of discrimination in a range of social contexts (Evers-Kiebooms et al., 2002).

The broader context: current health care policy

Another context in which Beverly's moral dilemmas around predictive testing can be further analysed is that of the broader health care policy context. Binedell and her colleagues (1998) noted recently "As predictive testing becomes more commonplace and receives greater public attention, public opinion and subjective norms may exert a growing influence on decisions about testing" (p.496). Similarly, Peterson and Bunton (2002, p.57) argue while discussing genetic testing within the context of citizenship "not only do people have a right to genetic information, but they have a duty to minimize or manage their own contribution to genetic disease. In line with new public health thinking and the imperatives of active citizenship more generally, citizens are expected to participate in the advancement of their own health and wellbeing" [Peterson and Bunton italics]. Within the broader contexts of Australian health care policy, economic directives and a utilitarian approach to the allocation of limited resources dominate current policy agendas (Palmer and Short, 2000) and thus individuals with known risks of serious inherited illnesses may be increasingly held accountable for generating "avoidable" long-term health costs given the availability of predictive genetic tests. Thus for individuals such as Beverly, the availability of predictive testing per se can, in itself, generate a range of moral imperatives around decisions to undertake such testing (Taylor, 2003). Further, it seems unreasonable that such availability, legitimised within mainstream medicine, can also generate such profound ethical dilemmas and responsibilities for individuals and families who are then essentially left to resolve them within the context of their own personal and life worlds. Whichever course of action Beverly undertakes in response to her dilemma about testing, she is at risk of moral censure from a range of sources including herself, her partner, her future children, her family and the broader society at large; this is in spite of the fact that one's genetic risks occur randomly and are not the product of factors such as wayward or "irresponsible" lifestyle for which some individual responsibility might technically be expected. It is clear that governments and commercially-driven biotechnological interests have much to gain from the development and widespread acceptance of technologies such as human genetic tests. The benefits enjoyed by these technological developments however, must also be accompanied by a sense of responsibility towards citizens who are impacted upon by such technologies and for whom complex ethical and psychosocial issues are generated.

Case study analysis and implications for the future?

Profound philosophical discussions abound in the literature about the potential impact of predictive medicine upon our core understand-

ings of such things as human-ness, identity and the body, and upon its potential to influence the creation of future people. Whilst all of these issues are highly relevant within the Huntington's Disease context, the case study described here has a more specific and applied focus, exploring a case study relating to an individual who, at 25% risk of HD, is forced to confront significant ethical complexities associated with predictive genetic testing. The writer's analysis in this instance draws primarily upon long-standing clinical genetic practice experience and sociological frameworks. While the case study refers to the context of testing for a mature-onset, single-gene disorder, are there broader lessons to be learned from this case study analysis?

In relation to Beverly, Jean and the rest of this family, their dilemmas, decisions and the aftermath of their decisions will, at the present time, primarily be experienced and resolved within the context of their own individual and family lives. Little is yet known about the impact of genetic test information upon relationships and families over the long term, although it is logical that such impacts may be considerable as well as long-lasting and that the dimensions of this issue will increase with the availability of more predictive tests. Some writers are already attempting to address such issues, and proposing models of care which take into account the familial contexts of genetic testing, as opposed to only individualized ones (Sobel & Cowan, 2000a, 2000b; Skene, 1998). In the longer term, longitudinal research is required to understand these dynamics and appropriate resources, education and support may need to become mandatory.

It also seems clear when considering this case study that in some circumstances, one autonomous family member's right "not to know" his/her genetic status can be severely compromised by another choosing to activate his or her own right "to know". This is clearly an issue of particular relevance to single-gene disorders in which a gene-positive test result for one member can be simultaneously conferred upon other biologically-related individuals. However, all genetic test information, by its very nature, involves inter-generational material which may have simultaneous relevance for multiple family members within a family context. How such information is delivered, interpreted and understood within a family context will be an increasingly important issue. Further, the relevance of the concept of genetic privacy within family contexts will also require active and ongoing consideration. The individual's dilemma within the family context as described here is further exacerbated by a clinical genetic services framework which is underpinned by bioethical principles and individualistic rights. Models of clinical genetics service delivery which can accommodate multiple simultaneous rights as opposed to single individual's rights only, seem eminently worthy of future investigation, in order to ensure that the "right not to know", upheld fervently as a theoretical ideal, can also be safeguarded in practice. The experience of the individual in the case study described here can also be illuminated by analyzing broader social values which may sanction the actions of an individual motivated by 'responsible' and altruistic intentions over those of an individual deemed perhaps to have less of such motivations. It is critical that the social contexts in which these complex new genetic technologies are located, are examined and made explicit for analysis, so that inherent contradictions and inconsistencies can be understood and that some groups of individuals are protected from unnecessary stigma and labelling.

Finally, the socio-political contexts in which predictive testing technologies are located are fruitful areas for ongoing analysis. Current health care policy is increasingly promoting individual self-management and the "prevention of the preventable". Such ideologies can generate particular vulnerabilities, and also moral dilemmas, for individuals with identified genetic risks, who have no control over their inheritance and who may not be able to intervene in any effective way to redress their apparent "deficits". Predictive genetic technologies therefore, need to be evaluated within frameworks of reference which are socially responsible and humane and which offer appropriate protection and support for the individuals and families for whom they are introduced and targeted.

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Endnotes

1 This is in contrast to 'polygenic' or 'multigene' disorders wherein more than one gene is implicated.

2 If one of these siblings was Beverly's identical twin, the case study as described would become very acute as a DNA genetic test would confer the same result upon each twin, given their identical genetic profile. Numerous accounts, in which one twin has requested a predictive test for HD whilst the other twin has elected not to be tested, have been noted in the literature; the ethical complexities of this situation are significant for all concerned, including clinical genetics service providers.

3 A gene-negative test result for Beverly however would not transfer to Jean who could still have the gene for HD but just not have passed it to Beverly (this is the basis of Beverly's 50% risk).

4 Whilst individuals such as Beverly may intend not to disclose their test result within a broader family context, this can in all likelihood be a difficult and even untenable position to maintain for an extended period of time (e.g. years).

5 The author has worked in clinical genetic testing services for a number of years.

6 For example, Beverly could delay testing until Jean's status becomes clear, or Jean could be encouraged to consider testing herself first if she knows that Beverly intends to proceed with being test

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