“You’re one of us now”: Young people describe their experiences of predictive genetic testing for Huntington disease (HD) and familial adenomatous polyposis (FAP)

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Running Title: You’re one of us now

Word Count: 4270

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Abstract
There has been much debate about the psychosocial impacts of predictive genetic testing in minors. The majority of this debate has been theoretical, with little empirical evidence published. We conducted in-depth interviews with 18 young people who had undergone testing, to explore the range of harms and benefits that they perceived were associated with their tests. Participants were eight individuals who were tested for Huntington disease (two gene-positive, six gene-negative) and ten who were tested for familial adenomatous polyposis (five gene-positive, five gene-negative). At the time of their test they ranged from 10 to 25 years of age. When interviewed they ranged from 14 to 26 years of age. Harms described included knowledge of future illness, witnessing distress in parents, negative impacts on family relationships and friendships, impacts upon employment and school, experiencing regret, feeling guilty and having to confront difficult issues. Benefits included knowledge of gene-negative status, relief from uncertainty, witnessing relief in parents, feeling able to plan for the future, positive impacts on family relationships and friendships, feeling empowered and experiencing a sense of clarity about what is important in life. Harms were described in relation to gene-negative test results, as were benefits in relation to gene-positive test results. The testing process itself had several positive and negative impacts for young people, distinct from the actual test result. Future research concerning the impact of predictive genetic testing in young people must remain broad and should aim to measure the beneficial as well as the harmful impacts that resonate for young people themselves.

Key Words. genetic predisposition testing, Huntington disease, familial adenomatous polyposis, adolescent, qualitative research, ethics.
INTRODUCTION

Predictive genetic testing of minors for adult onset conditions is a topic that attracts much controversy. The literature is replete with opinion pieces and theoretical debate about the ethical permissibility of allowing young people, under the age of legal majority, to access tests for conditions such as Huntington disease (HD). Absent from current literature is an adequate body of empirical evidence about the psychosocial consequences of such tests for young people (Duncan and Delatycki 2006).

Current guidelines recommend against predictive genetic testing in minors unless a clear medical benefit exists (Working Party of the Clinical Genetics Society (UK) 1994; International Huntington Association and the World Federation of Neurology Research Group on Huntington’s Chorea 1994; American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995; Genetic Interest Group (UK) 1995; American Academy of Paediatrics Committee on Bioethics 2001). This means that for conditions such as HD it is recommended that testing be deferred until the age of majority, or until young people are able to make an autonomous choice about testing. HD is a lethal neurodegenerative condition whose onset is usually in adulthood, for which no treatment is proven to alter the outcome (Walker 2007). We refer to these types of tests as tests with no medical benefit. For conditions such as familial adenomatous polyposis (FAP), testing occurs at younger ages. FAP is a bowel cancer predisposition syndrome where prophylaxis is available for those who are gene-positive. Testing is routinely performed in the early adolescent years, around the time of puberty (Rozen and Macrae 2006). We refer to these types of tests as tests with medical benefit.

Current guidelines are based on a premise of protecting young people’s best interests. Arguments against testing in minors generally fall into three categories. Firstly, it is claimed that testing young people fails to respect their future autonomy, denying them the opportunity to decide as fully competent adults not to know their genetic status. The second claim is that, when young people undergo testing, their confidentiality is breached as their test results are also disclosed to their parents. Thirdly, it is argued that significant psychosocial harms may occur as a consequence of disclosing genetic status to a minor (Duncan and Delatycki 2006).

This paper addresses the third of these categories, namely psychosocial harms. Our focus is mature young people who are old enough to be involved in the decision making process. The potential
psychosocial impacts of predictive genetic testing in young people have been discussed and debated at length in the literature. We review these arguments in detail elsewhere (Duncan 2004; Duncan and Delatycki 2006). The key point, however, is that these discussions are theoretical in nature. They are often based on the experience of people working in fields such as genetic counselling, ethics, medical genetics and social work. They also utilise evidence about the impacts of predictive genetic testing in adults. They are not based on empirical evidence about young people specifically.

Numerous calls have been made for empirical research about the impacts of predictive genetic testing in minors for adult onset conditions (Michie 1996; Clayton 1997; Dickenson 1999; Geller 1999; Hanson and Thomson 2000; Elger and Harding 2000; Duncan and Delatycki 2006). We are aware of only five published studies that have sought to measure the direct impacts of such testing in young people. The first is a case study in which a 5-year-old girl underwent pre-symptomatic genetic testing for maturity-onset diabetes of the young (MODY). Interviews were conducted with all family members and some of the health professionals involved (Shepherd et al. 2000; Shepherd et al. 2001). The other four studies concern predictive testing for FAP. One of these is also a case study in which 2-year-old and 4-year-old sisters were tested. This paper refers to the experiences of the parents only (Michie et al. 1996). The remaining three studies involve quantitative, psychological assessments of depression, anxiety and/or behavioural changes in young people tested for FAP (Codori et al. 1996; Michie et al. 2001; Codori et al. 2003). Together, these studies demonstrate little evidence of harm (Duncan and Delatycki 2006).

There are two significant problems with this current body of evidence. It is too small to base policy upon and it is heavily focused upon quantitative assessments of the negative consequences of testing. Potential positive consequences of testing have not been explored to the same extent and young people have not yet been given an opportunity to articulate the types of impacts – good and bad - that testing has created for them.

In the absence of adequate evidence, the stance taken in current guidelines relating to predictive genetic testing in young people is a cautionary one. It rests on the assumption that not testing young people creates less potential for harm than testing them. This assumption is not self-evidently true, and evidence is required to support or refute it. Moreover, we also know that testing of minors is occurring in
several countries around the world, contrary to guidelines, albeit without systematic follow-up (Duncan et al. 2005).

In this paper we report on 18 in-depth interviews conducted with young people who have undergone predictive genetic testing for either HD or FAP. We use their first hand descriptions to draw out a varied range of potential harms and benefits that such testing may have. These are the subjective impacts experienced by young people themselves. Having information about them is key to understanding what the psychosocial effects of predictive testing might be for young people and is crucial for designing appropriate outcome measures for future larger scale quantitative research.

**Rationale for the Study Design**

The ideal population of participants for this study would have been young people under the age of 18 years who had undergone predictive genetic tests for HD and similar conditions. As guidelines recommend against testing minors in cases where there is no medical benefit to the test, such cases are rare. We therefore chose to increase the upper age limit to 25 years, making recruitment feasible, whilst staying within the broad category of “young people” as defined by the United Nations (United Nations: Report of the Secretary-General 2003).

In addition to recruiting young people who had undergone testing for HD, we chose to recruit young people who had undergone testing for FAP. As noted above, FAP and HD fall into different categories of predictive tests. Testing for FAP has a clear medical benefit, whereas testing for HD does not. Predictive genetic tests for FAP in minors are permissible because the potential for psychosocial harm is regarded as being overridden by the existence of medical benefit (Andrews et al. 2006). This does not mean that harms and benefits beyond the medical benefit do not occur. Hence, the experience of young people tested for FAP is relevant at least to some extent, to the question of the effects of predictive testing where there is no medical benefit.

Past research in this field has utilised a narrow conception of harm and has rarely sought to measure benefit. The aim of this study was therefore to broaden the view of potential impacts associated with predictive genetic tests in young people. It is the range, rather than the frequency, of harms and benefits that we sought to document.
MATERIALS AND METHODS

Participants
Sixty-eight individuals were invited to take part in the study and 18 accepted, giving a response rate of 26%. Eight participants had been tested for HD (4 male, 4 female; 2 gene-positive, 6 gene-negative; between 17 and 25 years of age at the time of the test, between 20 and 26 years of age at interview). Ten participants had been tested for FAP (4 male, 6 female; 5 gene-positive, 5 gene-negative; between 10 and 17 years of age at the time of the test; between 12 and 25 years of age at interview) (Table I). Approval for the study was granted by the Royal Children’s Hospital Ethics in Human Research Committee, Victoria, Australia (reference number EHRC23065B).

Recruitment
Letters of invitation and a DVD were sent to potential participants from the clinical team. The DVD provided information about the study and was produced because pilot work with young people indicated that this was a medium young people were likely to give their attention to. A phone call was made to all individuals who did not respond to the letter.

Interviews
RED conducted semi-structured interviews at either the Royal Children’s Hospital in Melbourne, or at participants’ homes, between March and August 2004. RED was not aware of participants’ genetic status prior to conducting each interview. An interview theme list was used to ensure that all areas of interest were covered, while simultaneously allowing for flexibility based upon the participants’ individual experience and approach. Interviews were recorded using a digital audio recorder and files were downloaded onto a computer and transcribed verbatim.

Analysis and presentation of data
The interview transcripts were analysed using a combination of content analysis and thematic analysis. The governing approach was grounded theory, in which analysis is primarily guided by what emerges from the data itself, rather than by pre-existing analytic units derived from theory or from other studies. In this paper we present the findings from the first phase of analysis, which involved interpretive content analysis based on two units, harm and benefit. The second phase, which relies entirely on thematic analysis and
does not utilise specific units for content analysis, is presented elsewhere (Duncan et al. 2007). In interpretive content analysis, the units are not fully pre-determined or rigidly defined. The categories are somewhat open, and the researcher decides what will count as an occurrence of the unit, and codes accordingly (Hansen 2006). On the first round of coding, all content that could be categorised as either a positive or negative experience, associated with the predictive genetic test, was identified in the transcripts and coded as benefit or harm. In the second round, these two broad categories were then refined into sub-categories. This refinement was based on the themes that emerged within the sections of the transcript coded as benefit or harm. To enhance rigour, coding was independently undertaken by RED, MBD and LG. This process was organised using the qualitative research software package NVIVO (QSR International Pty Ltd, Victoria, Australia).

RESULTS
The results are presented in two broad categories: harms and benefits. These categories have then been separated into three sub-categories: (a) experiences relating to a gene-positive test result, (b) experiences relating to a gene-negative test result, and (c) experiences relating to the testing process in general. We have chosen one quote to illustrate each type of harm and benefit, although many of these were described by several participants. We aim to document the range, rather than the frequency, of harms and benefits articulated. Tables II and III summarise these.

Harms
(a) Harms associated with receipt of a gene-positive test result

- **Knowledge of future illness**
  “One day I will develop symptoms… I do have a genetic disease”
  *Belinda:HD:+ve*

- **Witnessing distress in parents**
  “When my dad realised I had it, he went and sat in the bedroom and didn’t come out for like 2 hours … that really upset me when I saw what it did to my parents”
  *Ali:FAP:+ve*

- **Identifying with other gene-positive family members**
  “She goes ‘you’re one of us now’, and I’m like, I don’t want to be one of you”
  *Kylie:FAP:+ve*
- **Experiencing a range of negative emotions**
  “I got a bit angry… um, shaky, very down, depressed”
  *Jason:FAP:+ve*

- **Feeling that the knowledge resurfaces at difficult times in life**
  “I had a new boyfriend… and it wasn’t going so well and you know, the HD and everything all just flooded back”
  *Belinda:HD:+ve*

- **Feeling distanced from family members**
  “It probably did distance [things] a bit with my father, just not being able to relate”
  *Jason:FAP:+ve*

- **Friendships being affected by negative mood**
  “My best friend, she did notice… I wasn’t really talkative”
  *Kylie:FAP:+ve*

- **Feeling let down by the reaction of others**
  “I’ve been let down by a couple of people who are… thoughtless, selfish”
  *Oliver:HD:+ve*

- **Experiencing anxiety about other people gossiping**
  “Everyone at work is yap yap yap yap yap, they all just create numerous stories”
  *Oliver:HD:+ve*

- **Experiencing concern about the implications for employment**
  “Concern about the workplace [is a worry]”
  *Oliver:HD:+ve*

- **Feeling regret about having the knowledge**
  “I would rather of not ever known”
  *Mark:FAP:+ve*

**(b) Harms associated with receipt of a gene-negative test result**

- **Experiencing unexpected negative emotions**
  “Directly afterwards I was flat for about a month, I just couldn’t do anything”
  *Zach:HD:-ve*

- **Worrying about the implications for siblings**
  “I felt that [brother] would get it… because I wasn’t, I thought that there’s more of a chance for him to get it”
  *Poppy:HD:-ve*

- **Feeling guilty**
  “I think I sort of felt a bit guilty because she ended up having it and I didn’t”
  *Liz:FAP:-ve*

- **Feeling distanced from family members**
  “[Mum] sort of let me go off and do what I’ve gotta do… we’ve drifted apart a bit.”
  *Ella:HD:-ve*
(c) Harms associated with the testing process more generally

- **Confronting the issue**
  
  “It makes it sink in a bit more… what mum’s going through at the moment”
  
  _Nina:HD:-ve_

- **Experiencing the stress placed on the family as a whole**
  
  “The stress on family… dad, mum, sister and that”
  
  _Troy:HD:-ve_

- **Experiencing Irritability**
  
  “Feuding all the time with my family, it wasn’t because of them, it was because of me… always thinking”
  
  _Travis:HD:-ve_

- **Feeling anxious while waiting for test results**
  
  “The waiting times [were the worst]… waiting to see what’s happened”
  
  _Jason:FAP:+ve_

- **Interference with school**
  
  “[Looking back] I wouldn’t have done [my final year of school]… I would have taken time out for myself”
  
  _Ella:HD:-ve_

- **Feeling a lack of control about the testing process**
  
  “Continuously going through counselling sessions when you just want to know what’s going on”
  
  _Travis:HD:-ve_

- **Experiencing anxiety about the needle used for the blood test**
  
  “The worst thing was the needle”
  
  _Kylie:FAP:+ve_

**Benefits**

(a) **Benefits associated with receipt of a gene-positive test result**

- **Experiencing relief from uncertainty**
  
  “We all knew, we just all knew, that was probably the best thing”
  
  _Ali:FAP:+ve_

- **Feeling able to move forward in life**
  
  “Allowing me to live my life… allowing me to accept that and just live”
  
  _Belinda:HD:+ve_

- **Bonding with other gene-positive family members**
  
  “I would definitely say that we share like a special bond and we’re closer now than we were before then”
  
  _Ali:FAP:+ve_

- **Strengthening friendships**
  
  “It kind of brought us closer because my best friend, she has diabetes … and now that I’ve got this, we can sort of… you know, I’ve got something… and she’s got something”
  
  _Kylie:FAP:+ve_
• Experiencing clarity about what is important in life
  “You realise when you go through that, I need to not take these things for granted”
  Ali: FAP: +ve

• Feeling a sense of control about managing the condition (related to FAP only, not HD)
  “Finding out that I had it… so there could be something done... was the best thing”
  Harry: FAP: +ve

(b) Benefits associated with receipt of a gene-negative test result

• Finding out that the genetic condition will not develop
  “Not having to worry [is] the best thing, knowing I’m clear, knowing I can’t pass it on”
  Sally: FAP: -ve

• Witnessing relief in parents
  “Mum can breathe too”
  Ella: HD: -ve

• Feeling able to plan for the future
  “You can sort of plan ahead, just for what you’re going to do”
  Troy: HD: -ve

• Experiencing relief from uncertainty
  “Finding out the result, just the result, I don’t care if it was positive or negative, but actually finding out”
  Ella: HD: -ve

• Feeling able to move forward
  “Directing my life… you know, ok, this is the direction I can take… I feel like I got the reigns, you know, before I had no idea what to do”
  Ella: HD: -ve

• Feeling generally more positive about life
  “I seem to have changed a bit, just come out of my shell … a bit happier and stuff”
  Troy: HD: -ve

(c) Benefits associated with the testing process in general

• Feeling Empowered
  “I respected myself a lot more after going through it all… I thought well, if I can go through this whole process, I can pretty much do anything”
  Travis: HD: -ve

• Developing awareness of the support that is available
  “The community and the friendship… I just found out was so solid through the process”
  Zach: HD: -ve

• Improved family relationships
  “Bringing the family closer… they were talking about it and being open about it and stuff”
  Emily: FAP: -ve
DISCUSSION

This study is the first to qualitatively explore young people’s subjective experiences of predictive genetic testing. Three key findings have emerged. Firstly, the range of impacts described by young people far exceeds the range of impacts that have been empirically assessed to date. Secondly, the distribution of harms and benefits is not fundamentally intuitive. Harms are not only associated with gene-positive test results and benefits are not only associated with gene-negative test results. Thirdly, the testing process itself can create a range of both harms and benefits for young people, distinct from the impact of the test result. These findings relate to mature young people, who are old enough to be involved in the testing process. They do not relate to cases where predictive testing occurs in much younger children who are not aware they are being tested.

In contrast to the very narrow range of harms and benefits that have been assessed in previous studies concerning predictive testing in young people, the majority of which have been harms, the range of impacts described in this study is extensive. Importantly, a significant number of these are beneficial consequences of testing. The impacts articulated by young people in this study relate to issues spanning family and peer relationships, plans for the future, mood, employment, schooling, emotional state, other people’s reactions, personal achievement and general approach to life. Many of these harms and benefits have been previously documented in adult populations, but this is the first time that such impacts have been documented in young people specifically. Previous research about the impacts of predictive genetic testing in adults has demonstrated a variety of harmful impacts. Some of these include depression and anxiety (Bloch et al. 1992) (Almqvist et al. 1999), the psychological burden of worry and guilt (Codori and Brandt 1994), identity difficulties (Tassicker 2005) and concern about the onset of symptoms (Timman et al. 2004). Past studies in adults have also reported several benefits associated with testing (Bloch et al. 1992) (Almqvist et al. 2003). These include greater closeness with family (Codori and Brandt 1994), a
healthy re-orientation in life (Wahlin et al. 1997), a desire to make the most of the present (Bloch et al. 1992) and being able to plan effectively for the future (Chapman 2002). A recent study in young adults aged between 18 and 35 years who have been tested for FAP also found evidence of impacts on education, friendships and social activities, relationship with other family members, and intimate relationships (Andrews et al. 2007). However, it is difficult to distinguish between the impacts of the predictive test itself and the impacts of FAP in the study.

The harms and benefits articulated by young people do not fall into what may be the most obvious intuitive categories, where harms are associated with 'bad news' and benefits are associated with 'good news'. Several harms were described in relation to gene-negative test results. These included feeling flat afterwards, feeling concerned about the implications for siblings, feeling guilty and feeling distanced from particular family members. Benefits were also described in relation to gene-positive test results. These included experiencing relief from uncertainty, feeling able to move forward in life, strengthened friendships, bonding with particular family members and experiencing a sense of clarity about what is important in life. Once again, similar findings have been documented in adults who have undergone predictive testing. Many studies have reported that adults who receive gene-negative test results following predictive genetic testing experience difficulties (Huggins et al. 1992; Tibben et al. 1992; Wahlin et al. 1997; Meiser et al. 2000; Williams et al. 2000; Michie et al. 2003; Tassicker 2005). Some of these difficulties have included guilt and concern for other family members (Nance et al. 1991), an awareness that other problems in life have not been eliminated (Codori and Brandt 1994), and a feeling of numbness (Tibben et al. 1993). Past studies have also reported that adults receiving gene-positive test results often fail to demonstrate the predicted increases in psychological distress or anxiety (Lawson et al. 1996; Almqvist et al. 2003). Benefits reported in adults following receipt of gene-positive test results include a greater awareness of the present (Bloch et al. 1992) and increased well being (Wiggins et al. 1992).

The testing process itself is also capable of creating harmful and beneficial impacts for young people, distinct from the actual test result. Positive impacts associated with the testing process included feeling empowered, developing an awareness of the support that was available, improved family relationships and undergoing counselling. Negative aspects associated with the testing process included having to confront the issue, experiencing the stress on the family as a whole, feeling irritable or anxious,
interference with school, feeling a lack of control over the process, and experiencing anxiety about the needle used in the blood test. Evidence about impacts of the testing process itself in adults is infrequent. Anxiety and distress during extended waiting periods has been reported (Bloch et al. 1992; Wilke 1995), as has a sense of relief from uncertainty following both gene-negative and gene-positive test results (Codori and Brandt 1994). However, most of the available evidence about predictive testing in adults focuses on the impacts of the actual test result.

These findings are important for clinicians and researchers alike. In consulting with young people about predictive testing, it is important not to focus only on the potential impacts of the test result, but also to discuss possible reactions to being tested per se. It would be helpful to prepare young people for the range of potential impacts that the test result may have and to forewarn them about ‘intuitively contradictory’ reactions, such as feeling bad or ambivalent after receiving ‘good news’, or feeling good in the face of ‘bad news’.

In this study, many of the types of harms described by young people are not different in kind from those found in studies of older adults. Future research would benefit from a focus on seeking to identify whether there are negative outcomes that have particular relevance to child and adolescent development. These may include, but are not limited to, impacts on peer relationships, impacts on family relationship (and support structures), identity formation and lack of understanding (Rice and Dolgin 2005). This study also focused on the psychosocial implications of testing, as opposed to the other two key objections; concern about future autonomy and confidentiality. Evidence about these concerns may have particular relevance to young people. Whilst this study has identified a range of potential harms associated with predictive genetic testing in young people, this does not necessarily imply that young people should be prevented from having testing. The risk of harm in itself is not a justification for denying access, as is exemplified in the current situation for adults. Adults are able to access predictive testing for a variety of conditions, even though they are exposing themselves to risks. In order to support a stance in which young people are not able to access tests in the same way that adults are able to, evidence is required demonstrating that the impacts for young people are worse than those for adults.
Limitations

This study is based on a small sample of young people who were all seen at the same genetics service and the response rate was low. Therefore, the experiences conveyed may not be representative. The descriptions provided by young people were retrospective, in some cases several years after their test. These descriptions are thus vulnerable to recall bias. Participants who take part in research may also be those who are coping best. Future studies would be strengthened by the inclusion of base-line measures in addition to several post-test measures, as well as by a wider sample population.

CONCLUSIONS

Empirical research about the impacts of predictive genetic testing in young people for adult onset conditions has relied on a theoretical discussion of potential harms and benefits in combination with published evidence about the impacts of testing in adults. The harms and benefits described in this paper, as articulated by young people themselves, now provide new impetus and direction for future research. Future research must measure a wide range of potential impacts of testing, both beneficial and harmful. It must also focus on impacts that will help to differentiate between the effects of predictive genetic testing in young people and the effects of such testing in adults. The list of potential outcomes presented in this paper may serve as a useful reference point in clinical discussions with young people requesting predictive tests in the future.

ACKNOWLEDGMENTS

We thank Ros Tassicker for her assistance with recruitment of participants. We also thank the young people who participated in interviews as part of this study. RED is an NHMRC Postdoctoral Research Fellow. MBD is an NHMRC Practitioner Fellow.
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Table I. Information about the participants

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<tr>
<td>Doug</td>
<td>FAP</td>
<td>Male</td>
<td>-ve</td>
<td>14</td>
<td>18</td>
</tr>
<tr>
<td>Mark</td>
<td>FAP</td>
<td>Male</td>
<td>+ve</td>
<td>16</td>
<td>21</td>
</tr>
<tr>
<td>Jason</td>
<td>FAP</td>
<td>Male</td>
<td>+ve</td>
<td>14</td>
<td>22</td>
</tr>
</tbody>
</table>

**SUMMARY**

<table>
<thead>
<tr>
<th>HD: 8</th>
<th>Female: 10</th>
<th>+ve: 7</th>
<th>Mean: 17</th>
<th>Mean: 21.8</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAP: 10</td>
<td>Male: 8</td>
<td>-ve: 11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* gene-positive test result       ** gene-negative test result
### Table II. Harms experienced by young people who have undergone predictive genetic tests

<table>
<thead>
<tr>
<th>Harms associated with gene-positive test results</th>
<th>Harms associated with gene-negative test results</th>
<th>Harms associated with the testing process in general</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Knowledge of future illness</td>
<td>- Experiencing unexpected negative emotions</td>
<td>- Having to confront the issue</td>
</tr>
<tr>
<td>- Witnessing distress in parents</td>
<td>- Worrying about the implications for siblings</td>
<td>- Experiencing the stress placed on the family as a whole</td>
</tr>
<tr>
<td>- Identifying with other gene-positive family members</td>
<td>- Feeling guilty</td>
<td>- Experiencing irritability</td>
</tr>
<tr>
<td>- Experiencing a range of negative emotions</td>
<td>- Feeling distanced from family members</td>
<td>- Feeling anxious while waiting for test results</td>
</tr>
<tr>
<td>- Feeling that the knowledge resurfaces at difficult times in life</td>
<td>- Experiencing anxiety about other people gossiping</td>
<td>- Interference with school</td>
</tr>
<tr>
<td>- Feeling distanced from family members</td>
<td>- Experiencing concern about the implications for employment</td>
<td>- Feeling a lack of control about the testing process</td>
</tr>
<tr>
<td>- Friendships being affected by negative mood</td>
<td>- Feeling regret about having the knowledge</td>
<td>- Experiencing anxiety about the needle used for the blood test</td>
</tr>
<tr>
<td>- Feeling let down by the reactions of others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Experiencing anxiety about other people gossiping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Experiencing concern about the implications for employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Feeling a lack of control about the testing process</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Experiencing anxiety about the needle used for the blood test</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table III. Benefits experienced by young people who have undergone predictive genetic tests

<table>
<thead>
<tr>
<th>Benefits associated with gene-positive test results</th>
<th>Benefits associated with gene-negative test results</th>
<th>Benefits associated with the testing process in general</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Experiencing relief from uncertainty</td>
<td>▪ Finding out that the genetic condition will not develop</td>
<td>▪ Feeling empowered</td>
</tr>
<tr>
<td>▪ Feeling able to move forward in life</td>
<td>▪ Witnessing relief in parents</td>
<td>▪ Developing awareness of the support that is available</td>
</tr>
<tr>
<td>▪ Bonding with other gene-positive family members</td>
<td>▪ Feeling able to plan for the future</td>
<td>▪ Improved family relationships</td>
</tr>
<tr>
<td>▪ Strengthened friendships</td>
<td>▪ Experiencing relief from uncertainty</td>
<td>▪ Undergoing counselling</td>
</tr>
<tr>
<td>▪ Experiencing clarity about what is important in life</td>
<td>▪ Feeling able to move forward</td>
<td></td>
</tr>
<tr>
<td>▪ Feeling a sense of control about managing the condition (FAP only)</td>
<td>▪ Feeling generally more positive about life</td>
<td></td>
</tr>
</tbody>
</table>
Box I. Summary

- The range of harms and benefits described by young people who have undergone predictive genetic testing is large and exceeds the range that has been empirically measured previously.

- This is the first time that such a range of harms and benefits associated with predictive genetic testing has been documented in young people.

- Harms are not only associated with gene-positive test results, but also with gene-negative test results and benefits are not only associated with gene-negative test results, but also with gene-positive test results.

- The testing process itself can create a range of both harmful and beneficial impacts for young people.