

ARTICLE

Quality in genetic counselling for presymptomatic testing — clinical guidelines for practice across the range of genetic conditions

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Presymptomatic testing (PST) is the performance of a genetic test on an asymptomatic individual at risk of a condition to determine whether the person has inherited the disease-causing mutation. Although relevant guidelines exist for specific diseases, there is no overarching protocol that can be adapted to any disorder or clinical setting in which such testing is offered. The objective of this European project was to develop a set of coherent guidelines for PST (for adult-onset monogenic conditions) for use by health professionals working in a range of disciplines, countries or contexts. To ensure the guidelines were appropriate and practice based, we organised a workshop attended by an expert group of practitioners with relevant health professional backgrounds from 11 countries. Models of service for offering PST were presented, the group then discussed different aspects of testing and the standard of care required to ensure that patients were prepared to make decisions and deal with results and consequences. After the workshop, several rounds of consultation were used with a wider group of professionals to refine the guidelines. The guidelines include general principles governing the offer of testing (eg, autonomous choice of the patient), objectives of genetic counselling in this context (eg, facilitation of decision making), logistical considerations (eg, use of trained staff) and topics to be included during counselling discussion with the patient (eg, consequences of both positive and negative outcomes). We recommend the adoption of these guidelines to provide an equitable structure for those seeking PST in any country.

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INTRODUCTION

Presymptomatic testing (PST) is defined as the performance of a genetic test on an asymptomatic individual to determine whether or not the person has inherited the disease-causing mutation.¹ The terms ‘predictive testing’ or ‘susceptibility testing’ may sometimes be used in the same context, but for the purposes of this paper we will use PST.

As recombinant DNA techniques enabled testing of samples through linkage analysis in the 1980’s, PST for a range of genetic conditions has been possible. For example, testing for Huntington’s disease had been possible via linkage analysis since before 1983,² although some patients preferred to have a more accurate direct test,³ which became available after the mutations responsible for this and other neurodegenerative disorders were identified.⁴ Later, as understanding of familial cancer syndromes increased, PST was offered to individuals at increased risk of breast and ovarian cancer,⁵ Lynch syndrome (previously termed hereditary non-polyposis cancer)⁶ and familial adenomatous polyposis.⁷

The information now available about specific disease-causing mutations has enabled PST to be offered for a much wider range of disorders and it may now be provided by health professionals outside of specialist genetic centres. For example, testing for the mutations that cause hypertrophic cardiomyopathy,⁸ or maturity onset diabetes of the young⁹ may be offered in cardiac and diabetes clinics, respectively. It has been noted that the philosophical and practical

approach to offering testing may differ between specialist genetic centres and other health services.¹⁰ It is therefore important that guidance is available on the requirements for PST for adult-onset conditions to ensure patient choice and safety.

BACKGROUND LITERATURE

Formal guidelines for offering PST in a clinical context were developed in 1989 and updated in 1994 by the World Federation of Neurology Working Group on Huntington’s disease and International Huntington’s Association,¹¹ and a second update has been published recently.¹² The guidelines are primarily for use with Huntington’s disease but can also be applied for other neurological conditions (eg, Alzheimer disease, frontotemporal disease, spino-cerebellar ataxia). The tenets of the document are that: the decision to take a test should be voluntary, without coercion from any other person, informed consent should be sought, the individual should have access to counselling of the highest quality and testing should be offered within specialist genetic units. Specific and highly detailed recommendations are made about the information to be given during pre-test counselling including information on the test procedure, alternatives and consequences. Post-test counselling sessions should be planned before the result is given and include the need for the counsellor to initiate contact after 1 month if it has not been made by the patient. Other authors¹³ refer to these

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prescriptive guidelines for use in PST conditions other than Huntington's disease, for example Panegyres *et al*¹³ refer to these in the context of testing for familial Alzheimer disease. The Huntington's disease model is also consistent with the guidelines adopted for testing for non-neurodegenerative conditions, such as hereditary forms of cancer^{14,15} and cardiogenetic conditions.^{16,17}

Dufasne *et al*¹⁸ described the use of the Huntington's protocol in detail after 15 years of experience in using it in Canada. In summary, the counselling was offered by a multi-disciplinary team comprising medical geneticists, genetic counsellors and psychologists. Before face-to-face contact the patients discussed their wish for a test by telephone with a psychologist. Following that call, three face-to-face contacts were made, the first (2 h) was with a psychologist to assess psychological readiness and needs of the patient. In the second (1 h), the patient was seen by a physician and the psychologist, to obtain medical history and confirm the diagnosis of Huntington's disease in the family. The third session (2 h) was conducted with a genetic counsellor. If the patient proceeded with testing, the results were disclosed at a fourth session and a follow-up consultation was arranged by telephone 1 week after the results were given. Of an initial 135 patients who requested testing, 40 withdrew during the pre-test counselling process. Of these, 18 withdrew after the initial telephone call with the psychologist and the authors attribute this to last minute self-selection, possibly by those who are highly ambivalent about their desire to be tested.

Brain *et al*¹⁹ gathered data on the protocols used by 16 genetics centres offering PST for Lynch syndrome. All centres offered a minimum of one pre-test counselling session, although the range was 1–3 sessions. Where more than one session was offered, the time period between them was four to 8 weeks. Staff of four of the centres reported, however, that more than one session was often unnecessary and that they had reduced the number of pre-test sessions to one or were planning to do so. A particular point was made that the situation differed from that of Huntington's disease, because families seemed more 'matter of fact'¹⁹ (p200) about the testing and did not want the testing procedure to be needlessly prolonged.

In a study of 271 adults tested for a Lynch syndrome mutation, Aktan-Collan *et al*¹⁰ noted that participants felt the strongest need for psychological support at the time of disclosure of the result, suggesting that having a personal friend or family member present might be useful in this regard. However, although bringing a support person to the results session had been recommended, only 30% of those in the study had done this. This highlights the conundrum between enabling choice and setting firm criteria for testing. In that study, pre-test counselling had included topics such as the actual mutation, methods of screening for tumours, benefits and disadvantages of testing and emotional responses to testing. At the post-test session, results were given as well as further reinforcement of information about screening for mutation positive patients and reminder of the population risk of colon cancer for those who were mutation negative.

Although sets of guidelines for offering PST have been developed, these relate to specific disorders or groups of disorders. In the current era of genetic and genomic health care, PST is available for increasing numbers of diseases, and is provided by health professionals working outside the genetic specialist clinics.^{8,9,20} There is no overarching protocol or guidance that can be adapted to any disorder or clinical setting in which PST is offered. The objective of the EuroGentest2 project is to ensure that genetic testing is provided equitably and safely to patients in Europe. One of the deliverables for the EuroGentest2 project is therefore to develop a set of coherent

guidelines for PST that can be used by health professionals working in a range of countries or contexts to ensure that patients are appropriately prepared for such testing and the consequences of the test.

METHODS

The leaders of the EuroGentest2 project work package are experienced clinical health professionals in the field of genetics. However, we felt it was important to utilise the experience of a wide range of practitioners from across Europe and so we used an expert group to develop guidelines for counselling when offering PST for adult-onset monogenic conditions.

Participants

Experienced practitioners were invited to attend a workshop to discuss, debate and formulate the key requirements for PST counselling. Practitioners with relevant professional backgrounds from 11 countries attended (Table 1). Of these, a core group of those who were highly experienced in PST counselling focussed on development of the guidelines. However, a wider group of practitioners contributed through discussion of the outputs.

Process

All participants were made aware of the focus of the workshop in the invitation to attend. A number of relevant publications^{17,21–23} were provided to each participant several weeks before the workshop and they were asked to read these before arrival to help them prepare for the discussions.

During the first session of the workshop, presentations were made by a medical oncologist offering PST in the context of familial cancer syndromes, a medical cardiologist providing PST to those at risk of cardiac genetic conditions and a nurse consultant who pioneered PST for monogenic forms of diabetes and set up a network to train professionals to offer such testing nationally. All three presented models of service for offering PST.

The entire group then discussed the terms of reference for the guidelines before splitting to discuss different aspects of service. The core group worked specifically on quality of genetic counselling to support PST. Twice during the workshop the groups reconvened for discussion and feedback from the wider group on the developing guidelines.

There will be occasions when PST may be offered to or sought by minors,^{24,25} but the expert group decided not to specifically address this

Table 1 Profession and country of workshop participants

Participant number	Professional background	Country
<i>Core group</i>		
1	Psychologist/psychotherapist	The Netherlands
2	Medical geneticist	United Kingdom
3	Medical geneticist	Czech Republic
4	Medical geneticist	Sweden
5	Medical cardiologist	France
6	Medical oncogeneticist	Spain
7	Representative of patient organisation (hereditary breast/ovarian cancer)	The Netherlands
8	Nurse Consultant in diabetes genetics	United Kingdom
9	Genetic counsellor	Norway
10	Genetic counsellor	Iceland
11	Genetic counsellor	United Kingdom
12	Genetics researcher	United Kingdom
<i>Additional group for consultation</i>		
13	Sociologist	The Netherlands
14	Laboratory geneticist	The Netherlands
15	Medical geneticist	Portugal
16	Medical geneticist	Spain
17	Medical geneticist	Sweden
18	Medical geneticist	Hungary
19	Community geneticist	The Netherlands
20	Genetic counsellor	United Kingdom
21	Health scientist	The Netherlands
22	Medical cardiologist	Sweden
23	Physician in primary care genetics	United Kingdom
24	Genetics researcher	The Netherlands

issue as other guidance exists, to which practitioners should refer.^{26,27} Following the workshop, the guidelines were circulated to all members for further comments and minor revisions were made.

RESULTS

The objective of counselling for PST is to enable the patient to make an informed and autonomous choice, to adjust to the results of the test (should the test be performed) in the context of his or her own life and utilise the results for health care management. For the purposes of these guidelines, PST is defined as testing of an asymptomatic adult for a mutation for a specific monogenic disorder. In these cases, where possible it is expected that the laboratory staff will aim to use a method that limits results to the clinical question being answered. However, if targeted mutation testing is not feasible, the possibility of other findings must be discussed with the patient before the test is performed and a disclosure strategy for any unexpected (incidental) findings agreed with the patient (for example, if whole genome sequencing is used, it would be possible to identify a BRCA1 mutation in an individual being tested for a neurodegenerative condition).

The principles provide a roadmap to autonomous choice. These include:

- (1) establishment of a respectful relationship between counsellor and patient, in which the patient's expectations, values and agenda have priority
- (2) employment of appropriately trained and skilled people to provide the counselling (see relevant documents)
- (3) provision of 'adequate' information (see content below) based on patient's needs and expectations, to include:
 - disease-specific information
 - psychological impact of testing
 - social implications of testing
 - legal implications of testing
- (4) enabling the patient to weigh the consequences and benefits in the context of his/her life (with relation to thoughts, values, beliefs, feelings)
- (5) Counselling that leads to autonomous choice
- (6) Counselling undertaken in the context of a professional code of conduct.

OBJECTIVES

The objectives of making PST available to unaffected (usually adult) family members at risk are to:

- (1) facilitate the patient in making his or her own decision about testing by giving information and supporting exploration of the context and consequences of the decision they make
- (2) provide the opportunity for self-management re:
 - health care
 - personal wellbeing and adjustment
 - reproduction
 - family communication.

LOGISTICS

It is important that an individualised approach is taken regarding the number and timing of counselling sessions, based on stage of maturation of patient rather than the particular disease. In general, a verbal (and if appropriate, written) summary of the issues discussed in counselling should be made at the end of each session and a letter

with relevant information about the disease and risk transference patterns for the family should also be provided to facilitate family disclosure.

The counsellor is responsible for making appropriate referrals and providing a comprehensive handover to other health professionals, including relevant psychological social or legal issues. The plan for co-ordination of care should be agreed with other health professionals.

It is assumed that health professionals providing PST will be appropriately trained and possess the relevant competences.²⁸ It is particularly important in the context of PST that health professionals recognise their own limitations and are able to make referrals to other health professionals (such as psychologists or psychotherapists) if required to support assessment of the patient or to provide the patient with psychological support.

(1) Pre-test counselling

Pre-test counselling is preferably done via a face-to-face conversation. The diagnosis, family history and risk to the individual will provide a foundation for the discussion. It should also include:

- information about the test and testing process, including likelihood of definitive results and what will happen to the remainder of the DNA sample after the test is performed
- the scope of the test and what it will show (and what it will not)
- the patient's perspective and wishes for and expectations of a test
- information about waiting time for test
- a clear indication of time between the sample being taken and disclosure of results
- opportunity to have a support person present during the pre-test, disclosure session and post-test sessions
- consent for testing and documentation of the decision
- an agreed method of conveying results (e-mail, phone, face-to-face, letter)
- the plan for follow-up after the results disclosure
- plans for disclosure to other family members
- information on support groups, surveillance and/or treatment
- specific issues of relevance to the particular disease
- implications for offspring (where applicable, to include discussion of reproductive choices)
- meaning of the possible results (technical and personal significance)
- relevance of the results to other relatives who may not have requested testing
- discussion of options available regarding screening and/or treatment and which of these could be used regardless of whether PST is performed
- discussion of psychological issues including coping with disclosure of test results, removal of uncertainty, residual uncertainty (where appropriate) and dealing with changed genetic status
- discussion of social issues including impact of testing (or not) on employment, insurance, personal and family relationships, privacy and confidentiality. This should include the implications of testing and/or results for the wider family, including partner or spouse
- the availability of follow-up and support after testing
- invitation for questions and offering of additional information as required.

The order of priority for discussion of topics will vary depending on condition or family situation.

(2) Post-test disclosure and counselling

Post-test counselling should include:

- appropriate disclosure of results, as previously agreed with patient
- discussion of plan for future contact
- re-iteration of information on support groups, surveillance, treatment, referrals to other practitioners or services and, where appropriate, participation in research projects
- the availability of follow-up and support.

In addition, some of the topics covered in the pre-test session may need to be revisited during the post-test counselling sessions; for example, the implications for the patient and relatives and discussion of the psychological impact of changed genetic status.

Note that the patient may prefer to receive results at a face-to-face meeting, by telephone, by letter or by electronic communication. This should be agreed during pre-test counselling. If the results are not delivered in person (face-to-face or by telephone), counselling should be offered. This should be offered regardless of whether the patient has a positive or negative mutation result, as it has been shown that patients who are mutation negative can also struggle with the psychological impact of the results.²⁹

DISCUSSION

PST has become available for a great variety of disorders. Where initially PST was offered mainly in the context of untreatable diseases (for the sake of pre-warning of the condition and psychological preparation for the future), it is now also used in situations where there is a greater perceived medical benefit from testing (eg, for conditions such as hypertrophic cardiomyopathy,⁸ maturity onset diabetes of the young⁹). It is important in all situations that individuals still make individual choices based on their own values, beliefs and preferences. As the study by Dufrasne *et al*¹² indicated, even those who actively request PST may be ambivalent about testing and appropriate counselling must be available to enable them to make informed choices. The overarching set of recommendations presented in this paper are consistent with those developed for specific monogenic neurodegenerative conditions^{10,11} such as Huntington's or Alzheimer disease, hereditary forms of cancer and hereditary forms of hereditary cardiac conditions, with the emphasis on voluntary action on the part of the patient and informed choice.

We emphasise that where appropriate disease-specific guidelines exist, they should still be used. However, there are a great many conditions for which PST is or will be available for which no such protocols have been prepared. The objectives, counselling content and logistical requirements have been documented here to provide a template for PST in a range of professionals and clinical contexts.

In developing these guidelines, the expert group deliberately focussed on the principles and objectives of PST rather than making prescriptions in terms of numbers of sessions of counselling. This enables practitioners to use their own professional judgement to individualise the process, as shown to be necessary by Brain *et al*¹³ The opportunity for support during and after disclosure is emphasised as this has been identified as an area of need by patients undergoing PST.¹⁴

The guidelines emphasise the involvement of appropriately trained professionals in offering PST. Although this will often mean genetic specialists such as medical geneticists or genetic counsellors, increasingly specialists in other secondary care settings will be providing PST. Their particular specialist knowledge is an obvious advantage in discussing the potential natural history of the disease and preventive

measures or management. However, the experience of practitioners working in other fields may differ in some respects from those working in genetics. For example, genetics specialists are constantly required to use an approach that involves consideration of the immediate and wider family³⁰ and because of the history of genetic counselling may be more practised in using a nondirective approach.³¹ It is therefore essential that all health professionals providing PST, whether in clinical genetics or other disciplines, should have appropriate education and training in the requisite skills to ensure patients are able to exercise freedom of choice and genuinely consider the implications of testing for themselves and their families. To this end, a set of core competences in genetic health care and relevant learning outcomes have been written for professionals working in a range of disciplines in primary, secondary and tertiary settings.²⁸ Of particular importance in the context of PST are the competences related to appropriate counselling skills and ability to offer psychological support to the patient. In order to attain these skills, specific education in counselling skills is required, as well as ongoing counselling supervision for professionals undertaking these tasks.

CONCLUSIONS

These recommendations have been produced by specialists in Europe for use in any setting where PST for genetic disorders caused by a single gene mutation is offered. The objective was to ensure testing was provided in a way that facilitated patient choice while maintaining patient safety. We recommend their adoption to provide an equitable structure for those seeking testing in any European country.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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