

An assessment of written patient information provided in a genetic clinic and relating to genetic testing in seven European countries



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Background

Genetic literacy amongst the general population is relatively low¹ making it imperative that oral information is supported by written material during the genetic counselling process. Used alongside verbal communication it has been shown to improve patient satisfaction² and knowledge³ and allay stress and anxiety⁴. A number of studies previously carried out to assess the quality of written patient information in this area found that risks and limitations of genetic testing were infrequently discussed⁵, images were not sufficiently clear and readability was poor⁶, and most materials did not contain basic information about the test itself⁷. There have however been no studies published that address this issues from a European perspective.

Method

•Written patient information relating to genetic testing was collected from 7 European countries which varied in terms of geographical location and service development. These were: UK, Netherlands, Poland, Sweden, Belgium, Italy and Germany.

•The information related to 5 genetic conditions which were chosen because they reflect a range of inheritance patterns, age at diagnosis and rare and more common conditions. These were: hereditary breast cancer, Duchenne muscular dystrophy, tuberous sclerosis, 22q11 deletion, connexin 26 alteration.

•Information was assessed for the inclusion or omission of 14 key issues identified through various information development tools^{7,8,9,10} and organised focus groups as being important for inclusion when providing information about genetic testing.

Results

•Key issues were discussed more frequently in pre-written leaflets than in personal letters (Figure 2).

•Psychological and social effects of genetic testing was discussed in only 18% of material, the majority of which related to hereditary breast cancer (Figure 1).

•Only 44% of material included benefits as well as risks of genetic testing (Figure 1). Benefits were mentioned more often (82%) than risks (48%).

•Sources of additional information and support were only discussed in 50% of the material (Figure 1).

•Material about hereditary breast cancer was more comprehensive than material about the other four conditions. Of the four items that included every key issue, all of them related to hereditary breast cancer, and all were pre-written leaflets.

Figure 1: Frequency of Key Themes in Written Material

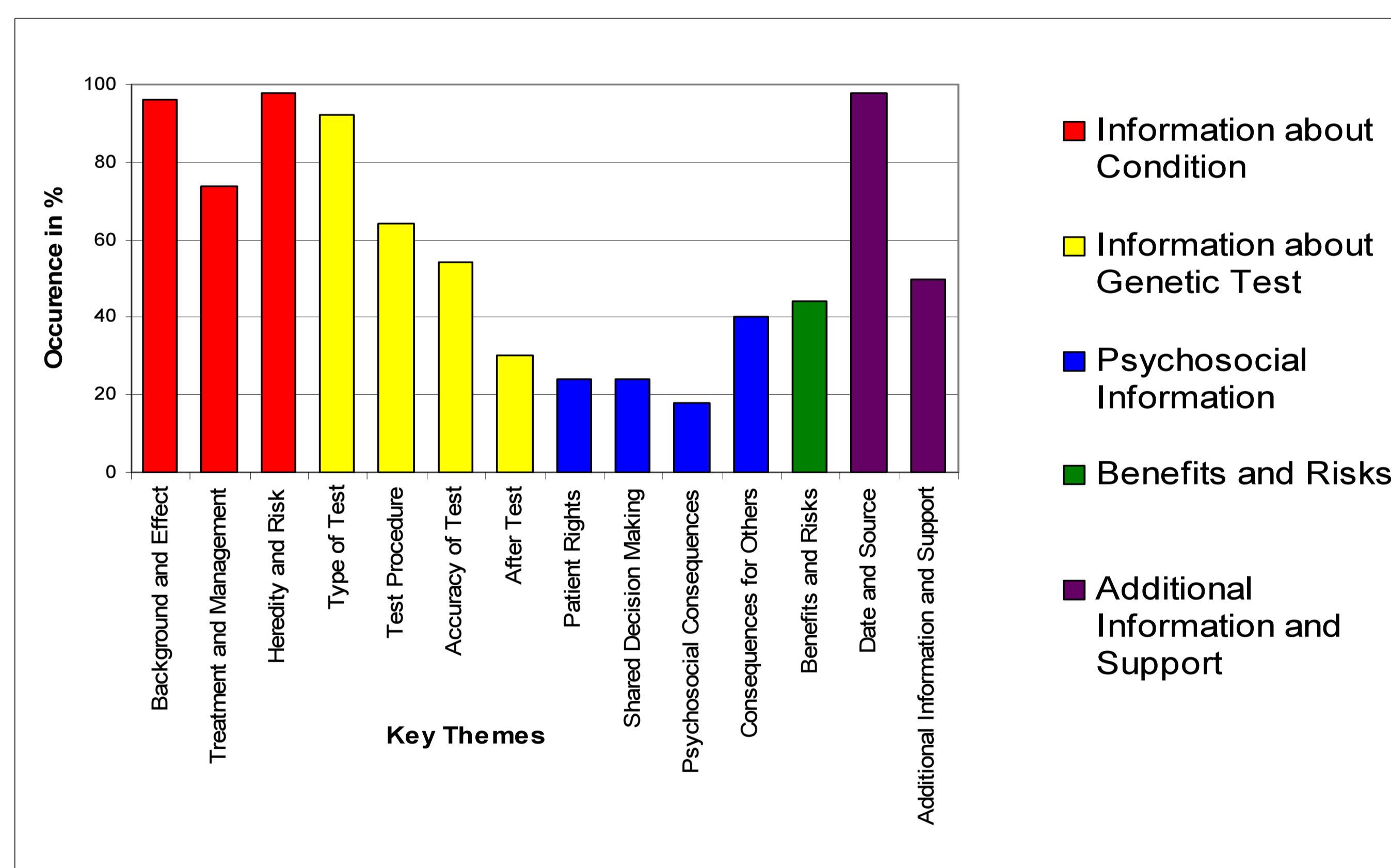
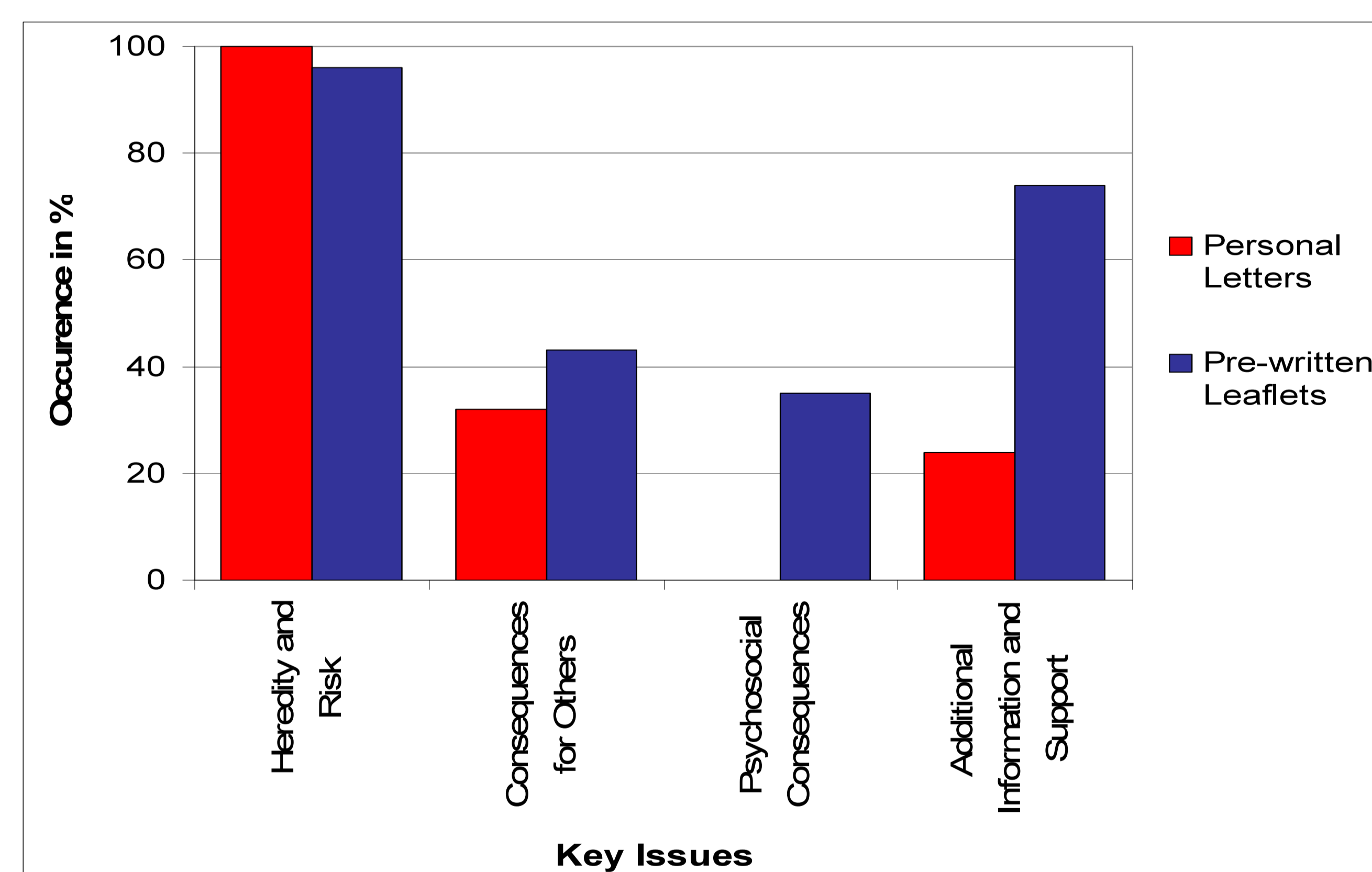


Figure 2: Comparison of Personal Letters and Pre-Written Leaflets



Discussion

The reason that personal letters were found to be less comprehensive than pre-written leaflets is likely to stem from a number of causes. The first may be the shortage of resources and time experienced by genetic services. They may also be sensitive to issues of confidentiality since clinical letters are often copied to other practitioners and possibly shown to other family members. Pre-written leaflets on the other hand can be assessed by patients and professionals during the development stage to ensure they cover all the key issues. In addition, pre-written leaflets are often prepared by patient groups and are hence patient driven. They may therefore be more likely to tackle the issues important to patients and families.

Information was far more likely to discuss hard, factual information related to the condition and the test, than the more qualitative, experience based information related to the psychological and social implications of genetic testing and this is a concern since studies have shown that patients do require psychosocial information. One reason for this may be that the acceptability and expectation of writing about psychosocial issues may vary considerably across the various cultures in the selected states. Another reason may be that clinicians believe this to be outside their remit, and consider it to be the responsibility of patient organisations or social services to provide this information.

Only half the written information assessed discussed where to obtain additional information, and how to contact support services and patient groups. This might be because additional information (such as complementary leaflets or patient information websites) may not exist in the patient's own language, or the clinician might be unaware of it. Alternatively the clinician may feel that he or she have given the patient and family all the information and support that is necessary. In some cases, additional support services or patient organisations may not exist.

Pre-written leaflets were only available from a limited number of genetic clinics contacted during the assessment. When we asked clinicians across the European Union whether pre-written leaflets about issues related to genetics would be of use to them, the vast majority said YES.

Further Work

In view of the key findings from this research, Unit 6 of the EuroGentest project (www.eurogentest.org) has been working towards a number of objectives:

•The development of a set of recommended key issues for inclusion in written patient information related to genetic testing.

•The development of a set of pre-written information leaflets for patients and families covering key issues related to genetics and genetic testing including a Frequently Asked Questions leaflets, information about what a genetic test is and a genetic glossary.

•This information has been developed with the help of patients and professionals to ensure that it is accessible, informative and tackles those issues important to patients and families.

•The leaflets will be translated into 11 languages over the next 3 years including Polish, Romanian, Bulgarian, Czech, Hungarian, Portuguese, Italian, Slovakian, Slovenian, Russian and Turkish.

•The leaflets will be disseminated across Europe in print and on line through genetic clinics, patient groups, national societies of human genetics and other relevant health bodies.

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