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NEWS AND COMMENTARY

Patient Information

Patient information for genetic testing

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Providing information for patients and families has always been a core activity of clinical genetics services. Traditionally, oral information has been given in a consultation, often followed by a personal letter. Patient information leaflets are sometimes, but not uniformly, used. The need for good quality patient information is now being recognised across healthcare systems and specialties. So what is the best way to provide information for patients considering or undergoing genetic testing? In a timely article in this issue,[1] Lewis and colleagues assessed the quality of written patient information about genetic testing for five different conditions (hereditary breast cancer, Duchenne muscular dystrophy, tuberous sclerosis, 22q11 deletion and the connexin 26 alteration) from a sample of seven European countries. They conclude that where possible, patient information leaflets should be made available to patients, and they provide a checklist of key issues to be included in written materials about genetic testing.

Providing written information has clear benefits for patients and families. Written information has been shown to reduce patient anxiety and may improve understanding and recall. Patients can keep the leaflet for later reference (40–80% of spoken information in a consultation is forgotten[2]) and can also use it to share information with other family members or health professionals outside genetics. There are also benefits for the clinician—allowing time to be spent on customising information for the individual patient rather than providing standard information, as well as ensuring that they meet good practice standards in an increasingly litigious society. Patient information leaflets can also play an educational role for health professionals outside specialist genetics services. Leaflets for the patient sent via the referring clinician with clinical letters or lab reports can be a useful source of 'just-in-time' information[3] for that health professional.

Despite these benefits, providing patient information materials is not straightforward. Appropriate leaflets may not be available and if a 'standard' leaflet is available, variations between countries and local contexts may make a lot of customisation necessary. Developing or customising patient information demands expertise in writing and presenting information as well as in genetics. This takes time, as does patient involvement. In addition, standard leaflets are written for the 'average' patient, and do not take account of an individual patient's level of understanding. Other factors need to be considered too, including accessibility – making written leaflets accessible (style, reading age, font, layout, paper, use of pictures and diagrams) and providing the same information for patients with, for example, a visual impairment or learning disability. Following development, production costs may also be an issue in clinical departments where budgets are always under pressure. Systems for quality assurance and updating will also need to be in place.

For this study, the authors surveyed existing tools for writing or assessing information on genetic testing and identified 14 key issues for inclusion: background and effect of the condition, treatment and management, heredity and risk, patient rights, type of test, test procedure, accuracy of the test, what happens after the test, shared decision making, psychosocial consequences, consequences for others, benefits and risks, date and sources, and where to find additional support and information. Many of these items and their descriptions were taken directly from DiscernGenetics,[4] the most comprehensive of the tools considered.

The authors assessed 50 pieces of material (aiming for two per condition per country) – personal letters, standard (template) letters, leaflets and books – provided by genetics clinics. One of their most notable findings is the number of key issues that were not well addressed: what happens after the test (only addressed in 30% of the pieces of material), shared decision making (24%), patient rights (24%), and benefits and risks of genetic testing (44%). Half of the pieces of material did not address sources of further information or support. While many materials addressed the benefits of testing (82%), less than half addressed the risks (48%), and possible psychological and social effects of genetic testing were covered only in 18% of the assessed materials. Only four pieces of material assessed in the study covered all 14 key items. All of these were about hereditary breast cancer and all were leaflets or brochures.

The study found that more key issues were discussed in pre-written patient information materials than in personal letters. These materials were more likely to include information about the accuracy of the test and about patient rights, and were more likely to address both the benefits and risks of testing. Possible psychosocial effects of genetic testing were not addressed in any of the personal letters and few provided any information about additional information and support. However, the study did not attempt to address the quality or effectiveness of information provided for individual patients, for example, whether or not personal letters were sent out with pre-written information leaflets.

This is the first study to compare written information for genetic conditions from a European perspective and it

provides a baseline assessment of the current position and contains a useful 'checklist' for those developing patient information about genetic testing. The authors indicate that Eurogentest will be developing, translating and disseminating information leaflets over the next 3 years. They recommend that written information materials should be routinely available for patients, as they provide a more comprehensive discussion of key issues than personal letters; that where these are available, they should be provided to patients with personal letters; and that the 14 key issues identified should be considered when materials are being developed, with particular attention paid to including information on risks and limitations and psychological and social aspects of genetic testing.

There is no doubt that written information materials can be helpful for patients. There are difficulties to be overcome, but where such materials can be made available, they have an important role to play in ensuring that genetics services provide a high-quality service for patients■

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