

## **The Patient's Contribution to Eurogentest**

Making sure that what doctor's said and do is what patients need, want and can use is crucial.

If you are a Surgeon your key skill is in cutting

If you are a Physician your key is in pills

If you are a Geneticist your key skill is in communication – because if patients don't understand they will not be to make use of the information generated by genetic tests and other diagnostic procedures.

When Genetic testing is needed we want to make sure that there is a basis for maximising the opportunity for effective communication. There needs to be a shared expectation or to what the outcomes might be.

If patients and families don't fully appreciate what is revealed by a genetic test, then the investment in research, development and clinical service delivery is largely wasted.

Need to know what information is helpful

How to deliver it

What to do with it

Scope, timing and quality of communicants has to be measured against the needs of patients and families to understand and make informed choices about their situation and the options open to this.

Very little attention has been given to this issue. This is surprising given the emphasis by geneticists on the importance of communication.

If you know what patients needs are and how they want them to be met, this will help to determine education and training needs of professionals so they can develop the necessary knowledge, understanding and skills to meet these needs.

EuroGenTest Unit 6 is developing a back to back framework for patients – guidance on information that might be helpful and professionals – how to prepare written information that is likely to communicate effectively what patients need to know.

Information about Genetics is scientifically complex and delivered in a stressful context. Patients and families need back up and support for the clinical encounter (before so they can prepare and after so they can follow up and take whatever action they feel to be appropriate and necessary).

The interpretation of patients in Eurogentest will ensure that this is recognised and acted on, thereby improving the quality and efficiency of genetic testing services. There are high levels of "pseudo literacy" and ignorance about genetics. Although many people have heard the terms used they are often confused about what they mean. DNA, gene, chromosome etc are often mixed up in people's minds. Patient organisations in EuroGenTest aim to develop strategies that will promote clarity and minimise the risk of confusion.

Otherwise there is a risk of communication failure. Stephen Hawking defines a Black Hole as "The point at which space and time cease to exist and matter becomes infinite". When you hear it, it sounds like an explanation, but although you may know the meaning of every word in this definition really understanding what the meaning of the whole is much more different.

Patient involvement in Eurogentest will help make sure that genetic testing is not a black hole for health gain, and that commitment is real, clear and to the point.

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