

Press Release: IMAGEMEND at the European Congress of Research Ethics Committees



IMAGEMEND provides new guidance for clinicians and patients in genetic testing in psychiatric disorders

by Thomas Wagner-Nagy

IMAGEMEND has played a vital role in this year's European Congress of Research Ethics Committees (EUREC), which was held in Barcelona from May 17-19. Several members of the consortium have debated and given insights into some of the most pressing ethical questions surrounding diagnostic and predictive genetic testing in psychiatric disorders as well as dealing with minors in clinical studies.

The IMAGEMEND team has developed and presented a checklist of sensitive and relevant points for clinicians to consider when selecting individuals for diagnostic and predictive testing. The aim of this catalogue is to provide guidance for both clinicians and patients with regard to diagnostic and predictive testing. "Our checklist contains the most important aspects that should be considered before carrying out a genetic testing", says Jana Strohmaier, a psychologist from the German Central Institute for Mental Health. She was closely involved in the ethics team who developed the list. The ethics team was led by Marcella Rietschel (Central Institute of Mental Health, Mannheim) and Dirk Lanzerath (German Reference Centre for Ethics in the Life Sciences, Bonn).

While genetic testing is becoming an increasingly important tool for research and disease prevention, it also comes along with risks, and even state-of-the-art scientific knowledge can only provide rough tendencies and probabilities as opposed to reliable predictions in many cases. Therefore, the process proposed by the IMAGEMEND team starts by individually assessing whether genetic testing is useful and advisable at all for the person concerned.

"Most importantly, we want to make sure that the patients understand the risks as well as the significance of the results", Strohmaier explains. "This also includes the patients' right not to be informed about incidentally identified disease risks that could have a negative effect on their lives, if they wish so."

The question whether patients and their close relatives who might also be at risk should be informed about incidental findings that are not related to the original purpose of the testing and only reflect probabilities to develop a certain disease is one of the most delicate dilemmas in this medical field.

"Our approach of extensive counseling is in stark contrast to the growing tendency of online lab testing in several countries, where people send in saliva samples for genetic testing and are then left alone with the results they receive via mail", Strohmaier added.

The checklist was developed by the IMAGEMEND Project's ethics team in close consultation with a range of experts, such as clinicians, geneticists, patients, relatives and legal advisors. It is constantly being amended and enhanced.



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