Genetic information: No choice for you

The following is an edited excerpt.

The American College of Medical Genetics (ACMG) has recently published recommendations for reporting incidental findings (IFs) in clinical exome and genome sequencing. These advocate actively searching for a set of specific IFs unrelated to the condition under study. For example, a two year old child may have her (and her parents') exome sequenced to explore a diagnosis for intellectual disability and at the same time will be tested for a series of cancer and cardiac genetic variants. The ACMG feel it is unethical *not* to look for a series of incidental conditions while the genome is being interrogated, conditions that the patient or their family may be able to take steps to prevent. This flies in the face of multiple International guidelines that advise against testing children for adult onset conditions. The ACMG justify this as "a fiduciary duty to prevent harm by warning patients and their families". They conclude that "this principle supersedes concerns about autonomy", i.e. the **duty of the clinician to perform opportunistic screening outweighs the patients right not to know** about other genetic conditions and their right to be able to make autonomous decisions about testing.

Read the full post here: No choice for you