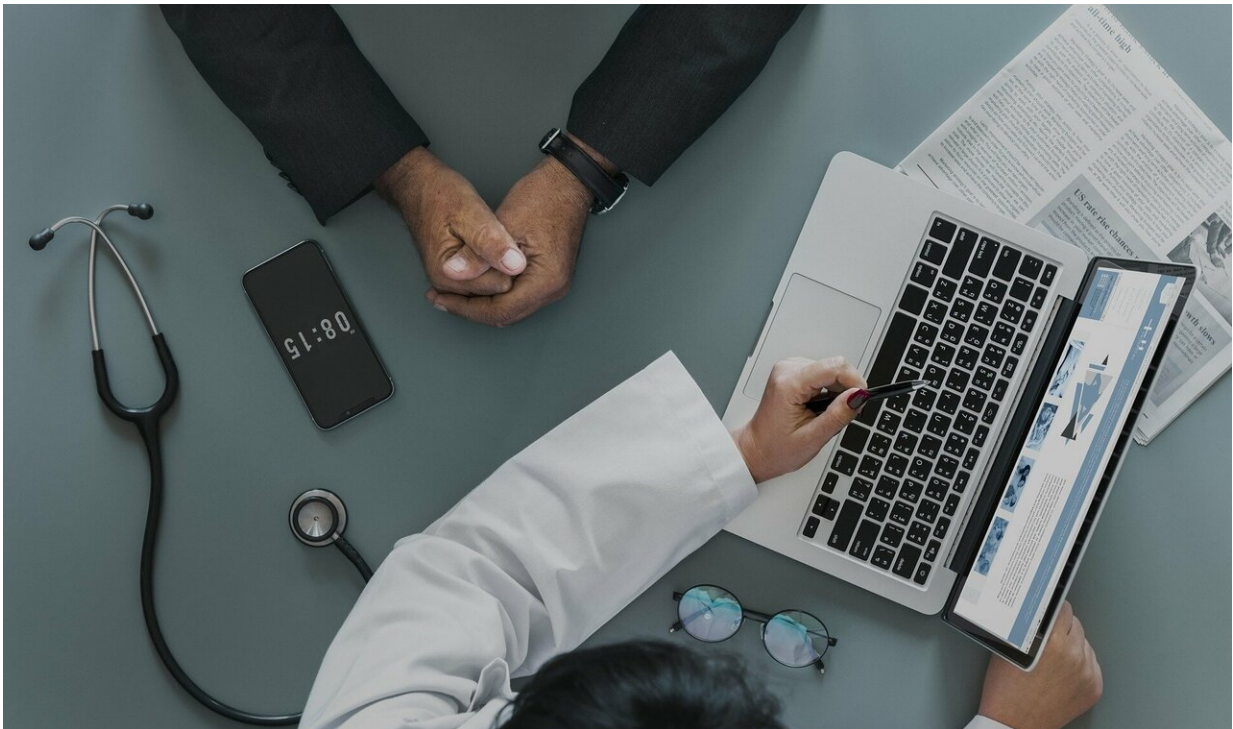


Better education needed for patients' improved understanding of gene therapies

December 8 2020, by Sophie Belcher



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A new review of research bringing together patient, carer and public views of cell and gene therapies has highlighted a need for appropriate education to better inform people including how clinical trials work and the risks and benefits of various treatments.

Over the last decade, new cell, gene and tissue-engineered therapies have been developed to treat various cancers, inherited diseases and some chronic conditions. They offer opportunities for the treatment of disease and injury, to restore function, and in some cases offer cures. In response the NHS' Advanced Therapies Treatment Centres (ATTCs) were set up to bring together the health service, academia and industry to address the unique and complex challenges of bringing these therapies to patients.

Led by experts from the Centre for Patient Reported Outcome Research (CPROR) at the University of Birmingham and the Midlands and Wales ATTC (MW-ATTC), the review, funded by a MW-ATTC grant from UK Research and Innovation is the first of its kind and the first to consider both patient and public opinions of cell and gene therapies.

Examining 35 studies, the majority of which were published between 2015 and 2020, analysis showed that a lack of understanding of the aims of clinical trials and overestimation of the potential benefits of cell and gene [therapy](#) were common among both patients and the general public. Patients were generally of the opinion that more information about participating in clinical trials is vital to enable them to make informed assessment of potential risks and benefits.

Older, [male patients](#) with more severe underlying conditions and a greater risk of death tended to be more accepting of new approaches such as [stem cell research](#) and generally, while views of therapies varied among patients, the provision of adequate information increased acceptance.

Interestingly the review also found that patients considered their clinicians to be the most trustworthy source of information which would suggest that patients would approach and discuss these treatments with their physicians. However, researchers found that this might not always

be the case due to a number of reasons including the perception that clinicians do not always approve of cell and gene therapies and may try to discourage them from pursuing treatment and may not have enough knowledge of the field to provide adequate advice.

Lead author Dr. Olalekan Lee Aiyegbusi, Co-Deputy Director of the Centre for Patient Reported Outcomes Research (CPROR) said: "The findings from this research are intended to inform the patient engagement work of the ATTCs. We hope that by highlighting various issues, efforts will be made to correct misconceptions, and improve the awareness of patients and the public about the potential benefits and risks associated with cell and gene therapies.

"It is important that the public and patients are aware of these therapies, understand the issues involved, and can contribute to the ongoing debates. A high level of awareness will also enhance [patients'](#) ability to make informed decisions about participating in [clinical trials](#) and routine administration of cell and gene therapies."

The full paper, "Patient and public perspectives on cell and [gene therapies](#): a systematic review," was published today (Tuesday 8 December 2020) in *Nature Communications*.

More information: Olalekan Lee Aiyegbusi et al. Patient and public perspectives on cell and gene therapies: a systematic review, *Nature Communications* (2020). [DOI: 10.1038/s41467-020-20096-1](https://doi.org/10.1038/s41467-020-20096-1)

Provided by University of Birmingham

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