A patient at the table: How partnership with patients improves research and enhances service delivery

Patients with rare diseases frequently have to embark on a long and challenging journey to access experts in the condition affecting them or someone they care for - a child or a family member. Commonly patients experience long delays before they receive a diagnosis. When they do, there may be little that can be done to alter the trajectory of the disease that affects them, and if there is there may be no guarantee that they will be able to access it. In this talk, I will explore how involving patients in all stages of research and development and in the planning and delivery of services that will maximize the possibility for improved health gain for those affected, and also make the best use of scarce expertise and precious resources.

Biography

Alastair Kent was the executive director of Genetic Alliance, United Kingdom, the British umbrella body for over 200 patient groups supporting that with rare and genetic disorders. Since retiring from Genetic Alliance, United Kingdom he has continued his involvement as an independent advocate in health policy and service development that will improve support for those affected or at risk from these conditions.

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