

HIPS/26/1031 - Long-term Health Impacts of Cancer Immunotherapy in Scotland: A National Data Linkage and Patient-Reported Outcomes Study (E-IMMUNE-PRO)

Cancer immunotherapy uses the body's own immune system to fight cancer and has transformed survival for thousands of Scottish patients, with over 10,000 treated in the last decade and numbers rising rapidly. However, these treatments can cause side effects known as immune-related adverse events (irAEs), which are common and can persist long after treatment ends. These may include conditions such as thyroid problems, joint pain, skin disorders, and fatigue, creating ongoing health and support needs. Despite this growing problem, we lack good evidence on what happens to patients in the long term. This study has three parts. First, we will link Scotland's national health records to map the pattern of side effects, how often patients use health services, and, for the first time anywhere in the world, what social care support they need. Second, we will survey 2,000 immunotherapy survivors to hear directly from patients about their quality of life, symptoms, and unmet needs. Third, we will build the systems needed to monitor these outcomes on an ongoing basis. Scotland is uniquely placed for this research because its health records can be linked across hospitals, GP practices, cancer registries, and social care in a way that is not possible elsewhere. Findings will shape how Scotland develops follow-up services for immunotherapy patients, inform a digital self-management tool (E-IMMUNE), contribute to UK and international treatment guidelines, and provide the evidence needed to ensure fair and effective long-term care for this growing patient group.