Working Group 3
Implementation of long-term follow up measures of children and adolescents receiving new anticancer drugs

Led by Danielle Horton and Raphaël Rousseau

Composition: Bouchra Benettaib, Ellen Bolotin, Davy Chiodin, Danielle Horton Taylor, Brice Fresneau, Wouter Hanekom, Jaap den Hartogh, Riccardo Haupt, Lars Hjorth, Yannick Kerloeguen, Leontien Kremer, Peter Lack, Ruth Ladenstein, Jürgen Maares, Koen Norga, Raphaël Rousseau Nicole Scobie, Rod Skinner, Gilles Vassal

Executive Summary:

Conventional treatment for children and adolescents with cancer has seen increasing success in the last four decades with five-year survival extending to 80% in some malignancies. However, more than 75% of childhood cancer survivors suffer long-term, often serious and life limiting, sequelae. There is consensus that long-term follow-up for such children is necessary to manage adverse effects and further to provide multi-level support as children transition to adulthood.

Evidence is also slowly accumulating which indicates that new and novel treatments for cancer may also have long-term adverse reactions in children, and the use of combination therapies – including old and new therapies – adds to the complexity of gathering data on these sequelae. It is therefore important to ensure that such effects are well documented from treatment, through childhood, adolescents and into early and later adulthood. Besides this, it is clear that much greater support is needed for childhood cancer survivors to overcome the barriers they face as they enter adulthood, in order to ensure as good a quality of life as possible.

Such long-term follow-up is not part of the current remit of clinical trials, nor is it provided through primary care. It is thus clear that changes to clinical trial design and alternative models of longer-term care are needed for all children treated with approved or experimental agents. The ACCELERATE platform, through one of its multi-stakeholder working groups, seeks to explore the potential for such long-term follow-up, looking at the views, proposals and needs of all stakeholders – parents/CCS, industry, academia and regulatory bodies.