

Executive Summary Joint Working Agreement - National Adult Congenital Heart Service, Ireland

Partners: This is a joint working agreement between Actelion Pharmaceuticals UK & Ireland Ltd; and The National Adult Congenital Heart Service (NACHS), The Mater Misericordiae University Hospital (MMUH); and The MMUH Cardiovascular, Respiratory, Renal, Diabetes and Endocrine Directorate (CVRRE).

Objective: The overall aim of the project is to jointly fund a congenital heart clinical nurse specialist to ensure the NACHS has the resources required to run an additional weekly clinic, thereby increasing the unit's capacity to manage patients with PH associated with congenital heart disease (CHD) appropriately, and freeing up the current clinical nurse specialist to begin the implementation of her Advanced Nurse Practitioner (ANP) Qualification, which will also increase the service's capacity in the longer- term.

Funding arrangement: Actelion is funding the first year and the MMUH the second year of this two-year project (October 2017), with the CVRRE providing resources such as clinic space, a PH consultant, administrative and organisational support for the additional clinic as well as line management of the specialist nurse.

Benefits to patients include: reduced wait times for initial and follow-up appointments; and increased consultation times.

Benefits to MMUH and CVRRE include: increased amount of time that healthcare professionals can spend with PH-CHD patients; increased patient satisfaction through reduced wait times; and maintenance of status as the National Adult Congenital Heart Service provider.

Benefits to Actelion include: increase in number of patients being prescribed and receiving the benefit of PAH therapies in line with international guidelines.

The NACHS and the CVRRE at the MMUH have indicated their intent to sustain the specialist nurse post long-term following the conclusion of the joint working agreement.