

Executive Summary Joint Working Agreement - National Pulmonary Hypertension Unit, Ireland

Partners: This is a joint working agreement between Actelion Pharmaceuticals UK & Ireland Ltd; and The National Pulmonary (PH) Hypertension Unit, 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 PH nurse specialist to ensure the national PH service has the resources required to run an additional weekly clinic, thereby doubling the unit's capacity to manage PH patients appropriately, and freeing up the current clinical nurse specialist to commence her Advanced Nurse Practitioner (ANP) Training, 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 (commenced 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; access to follow-up appointments at their local hospital rather than in Dublin; access to all available PAH treatments through increased capability of the unit to offer intravenous treatments; increased access to clinical trials.

Benefits to MMUH and CVRRE include: increased throughput of PH patients thereby reducing wait times; ability to offer an outreach service to referring hospitals; reduction in complaints from referring physicians about wait times; increased patient satisfaction through reduced wait times.

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

The National PH audit 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.