Newsletter for stakeholders

COST ACTION Harmonis@tion

The European Cooperation in Science and Technology (COST) Action CA20122, entitled "Harmonis@tion", is changing the way adrenal tumours are diagnosed, investigated and treated in Europe. This ambitious, multidisciplinary initiative, spanning 30 countries with more than 200 participants, enters its final year with a growing coalition of clinicians, researchers, experts in artificial intelligence (AI), data science and privacy, legal and ethics experts and patient advocates all working towards a single goal: a harmonised, equitable framework for adrenal tumour treatment and research.

Introduction and objectives

The Action, coordinated by Prof. Darko Kaštelan, which started on 28 September 2021 and will be completed on 27 September 2025, was launched with the aim of creating a multidisciplinary network to harmonise the clinical treatment and research of adrenal tumours across Europe. The purpose of this action arose from the fact that the treatment of adrenal tumours in Europe is heterogeneous, leading to significant inequalities in patient care. The focus of this action is on the COST Inclusiveness Target Countries (ITCs). A further aim was to create a modern framework for the development of a new generation of randomised real-time clinical trials to be conducted on the basis of registries.

The Harmonis@tion campaign has reached several important milestones:

- Educational events (Adrenal Tumour Masterclass) were organised twice a year (one online and one in person) focusing on new markers, multi-omics, genetics, diagnostics, therapies, biobanking and regulatory frameworks for cross-border data use,

- Promotion of knowledge exchange and development of a common research agenda on adrenal tumours at European level,

- The fourth round of Short-Term Scientific Missions (STSMs) is currently underway, offering young researchers the opportunity for cross-border collaboration and research,

- Engaging and training clinicians and young scientists, especially ITCs, to create the next generation of adrenal experts,

- Encouraging the involvement of new researchers and other reference networks,

- A series of AI-supported clinical registries are currently being developed, with a pilot phase to be completed by the end of 2025,

- Registry-based clinical trials are planned - a novel concept that combines real- world data with the rigour of clinical research.

Harmonis@tion is organised into five working groups:

1. Harmonisation of clinical practise in adrenal tumours;

2. Harmonisation of adrenal tumour research and omics;

3. Harmonisation of information technology (IT) and artificial intelligence (AI) tools with the aim of a standardised registry;

4. Harmonisation of the ethical and legal framework required for federated European studies;

5. Communication, dissemination and public involvement.

To achieve this, regular group meetings were held.

A joint effort

Harmonis@tion has approached the evolving challenges of clinical data sharing with a unique and bold perspective— asking difficult questions and daring to reshape the way we

think about collaboration. At its core, this initiative brought together clinicians, basic scientists, AI experts, data governance specialists, and legal and ethics experts to co-create a roadmap for a future where clinical data sharing is not only feasible, but also responsible and in line with modern regulatory standards. What really sets Harmonis@tion apart is its inclusive spirit. Our dialogue went beyond academia and fostered meaningful exchanges with patient advocates, industry representatives, hospital leaders and others who ultimately benefit from scientific knowledge. The insights gained about the current situation — particularly the differences between IT and non-IT environments — have proven critical to local and regional progress.

A widely implementable solution

One of the core innovations of the project is the elimination of centralised data copies once the analysis has been completed. This principle brings several benefits: significantly lower infrastructure costs, clearer management of intellectual property and liability, and full alignment with ethical and GDPR requirements by preventing unauthorised re-use of data. By keeping data local and re-engaging centres for each new research question, we improve the scientific rigour of studies — variables are defined after the hypothesis, not before. While regulatory complexity and legal agreements remain hurdles, the Harmonis@tion framework provides a streamlined, harmonised way forward. Importantly, the insights gained here are not limited to adrenal research. They offer a scalable, federated model that can be applied to any rare disease where multi-centre collaboration and interoperability are critical to progress.

A path to growth and collaboration

Short-Term Scientific Missions (STSMs) are one of the most effective tools within the framework of COST Harmonis@tion. They enable young scientists to visit host institutions across Europe to learn new techniques, exchange methods and gain access to resources that are not available in their home centres. At a time when inequalities in research infrastructure, funding and socio-economic conditions are increasing, STSMs are an important mechanism for equitable career development in endocrinology. Several young scientists have benefited from these missions under the Harmonis@tion action, taking the opportunity to expand their expertise and build cross-border collaborations. One of these missions culminated in the high impact publication “How ready are endocrine scientists to share retrospective clinical data for research: a perspective from the European Network for the Study of Adrenal Tumors” in the European Journal of Endocrinology— a testament to the tangible scientific and collaborative value created by this initiative.

What comes after Harmonis@tion?

As we approach the end of the project, we are focussing on legacy and sustainability. A structured plan is being developed to ensure the continued growth and adoption of the Federations_of_data model. This includes embedding it into the clinical research infrastructure, identifying long-term funding pathways and fostering collaboration with hospitals, data platforms and policy makers. At the same time, we will intensify our communication and dissemination efforts to increase reach and engagement. Through stakeholder mapping and targeted strategies, we are strengthening relationships with the scientific community, healthcare professionals, patient groups and beyond. Looking to the future, this initiative aims to be more than just a successful project — it aims to become a blueprint for trustworthy, efficient and ethical data collaboration in all areas of biomedical research. The upcoming final conference — the Joint 24th ENS@T Scientific Meeting and the 4th Harmonisation Meeting — will take place from 3 to 5 September 2025 in Belgrade, Serbia. The conference will not only provide a space for the presentation of results, but also an important opportunity for joint reflection, co-creation and forging coordinated strategies for the future.

Harmonis@tion