PRESS RELEASE: EHDS Plenary vote: Startups advocate for unrestricted access to health data to enhance innovation.

[Brussels, 14 December 2023, contact maxime@alliedforstartups.org] Allied for Startups welcomes the adoption of the European Parliament’s report on the European Health Data Space, a landmark initiative that underscores a pivotal opportunity for startups to drive innovation and revolutionise healthcare in the EU. However, the European Parliament’s report misses a golden opportunity to deliver on the secondary use of health data. This risks hampering startups’ ability to provide patients and healthcare professionals with innovative health solutions, especially for rare diseases, with no privacy benefit.

By allowing startups to securely access anonymised or pseudonymised health data for secondary use, the EHDS can empower them to develop new, innovative technologies and digital health solutions. These offer to enhance patient care and improve treatment outcomes, while driving research and innovation within the healthcare sector.

The opt-out mechanism introduced by the European Parliament will inevitably deprive the startup ecosystem of the tremendous opportunity to develop and scale their innovative and patient-focused products and services, whilst providing no privacy benefit for the citizen as these data are fully anonymised. Allied for Startups’ EU Director Inés Moreno-Alonso commented: "We commend the European Parliament’s commitment to creating a European Health Data Space but remain concerned about the creation of unnecessary hurdles that startups would face in case access to health data is restricted, and the impact it would have on innovation."

Maximising the pool of high quality health data and preserving patients’ privacy is possible considering that these data would be anonymised and shared in a secure, GDPR-compliant way. Allied for Startups therefore remains committed to engaging constructively with policymakers during the trilogue negotiations and will keep advocating for a regulatory framework that boosts Europe’s global competitiveness in medical research and innovation.

Allied for Startups is a worldwide network of over 40 advocacy organisations focused on improving the policy environment for startups. Our mission is to ensure that the voices of startups are heard in government. For more information on Allied for Startups including a full list of our network, visit the website at www.alliedforstartups.org