

IMI2 Project 101005122 - DRAGON

The RapiD and SecuRe AI enhAnced DiaGnosis, Precision Medicine and Patient EmpOwerment Centered Decision Support System for Coronavirus PaNdemics

WP2 – Patient empowerment through decision support systems

D2.1 Citizen and patient stakeholder advisory group

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Abstract

To develop a group that represents the patient stakeholder perspective and that will be integrated into the working groups of the consortium assuring that the patient perspective and patient empowerment remains central to the approach of this consortium.

Methods

A COVID-19 Patient Advisory Group has already been formed, comprising patients and patient representatives. Some have had COVID-19 and others are people with lung conditions who are concerned about catching the virus. From this, a sub-group has been created to feed into discussions on the DRAGON COVID-19 conference. In early 2021 we will put out a call to the group for representatives to sit on DRAGON WP2 and the project integration team, with a view to having two representatives for each. If more than two representatives are interested, we will discuss with the WP teams to ensure a good mix of experience.

Results

COVID-19 Patient Advisory Group members:

name	Country	Background
Removed from report due to GDPR	UK	Respiratory patient, volunteer with Asthma UK and British Lung Foundation, had COVID-19 (unconfirmed)
	UK	Respiratory patient, had COVID-19 (unconfirmed), founder of Long Covid support group
	Netherlands	Respiratory patient, volunteer with Longfonds
	Spain	Patient representative, President of the Association of Support and Information for Relatives and Patients with Pneumonia
	UK	Respiratory patient, volunteer with Asthma UK and British Lung Foundation
	UK	Patient, had COVID-19 (unconfirmed), has long COVID-19 symptoms
	UK	Patient, had COVID-19, worked as a researcher in healthcare
	UK	Patient, had COVID-19
	UK	Patient, had COVID-19 (unconfirmed), works as a Policy officer in Health Policy
	UK	Respiratory patient, volunteer for Pulmonary Fibrosis Trust
	Pakistan	Patient representative, Professor of Pediatrics
	Italy	Respiratory patient, represents Italian Bronchiectasis Association
	Sweden	Patient representative, Cystic Fibrosis Europe
	United Arab Emirates	Respiratory patient, had COVID-19, Assistant Professor of Cardiopulmonary Sciences
	Netherlands	Patient, had COVID-19
	UK	Respiratory patient, volunteer for Asthma UK
	Bulgaria	Respiratory patient, President of Bulgarian Society for Patients with Pulmonary Hypertension

Removed from report due to GDPR	Ireland	Respiratory patient, volunteer for Irish Asthma Society
	UK	Respiratory patient, had COVID-19 and was hospitalised
	Italy	Respiratory patient, President of Union of Lung Transplant Patients, Padova
	Belgium	Patient representative, European Federation of Allergy and Airways Diseases Patients' Associations (EFA)
	Spain	Patient representative, Spanish Federation of Allergy and Airways Diseases Patients' Associations (FENAER)
	Portugal	Respiratory patient, volunteer for Portuguese Lung Transplant Association
	UK	Patient, had COVID-19
	Kenya	Patient representative, Founder & Chairman of Allergy & Asthma Organization of Kenya
	Poland	Patient, had COVID-19
	UK	Respiratory patient, volunteer for Asthma UK
	Netherlands	Carer of respiratory patient, member of Stichting LAM Nederland
	USA	Respiratory patient, volunteer for Foundation of Sarcoidosis Research
	USA	Patient representative, President and Chief Executive Officer of Allergy & Asthma Network

Discussion

Recruitment for the group will continue to ensure a wide-ranging group that can respond to the needs of the project. Different individuals will be responsible for being involved in different tasks.

Conclusion

A Citizen and patient stakeholder advisory group has already been set up and started working for the DRAGON project. This group will continue to grow and ensure that the project is meeting the needs of the people it is serving.