

Joint press release by

- Amsterdam UMC
- The European Society for Intensive Care Medicine (ESICM)
- The Dutch Society for Intensive Care Medicine (NVIC)



Amsterdam UMC makes data about intensive care patients available to save lives

Amsterdam UMC is the first hospital in Europe to make intensive care patient data available for scientific research and healthcare improvement. It is not reasonably likely that individual patients are identifiable from these data. A total of almost one billion data points are available, mostly from connected monitoring devices. Using these big data, doctors and scientists from around the world will be able to develop algorithms using artificial intelligence techniques including machine learning. These will help to ensure that future intensive care patients receive the right treatment faster. This is an urgent challenge, as up to 30% of intensive care patients still die. That means hundreds of deaths in Europe every day.

European initiative

This development was initiated by the European Society for Intensive Care Medicine (ESICM) with the creation of its Data Science section and is supported by the Dutch Society for Intensive Care Medicine. They encourage other hospitals to follow this example. "Sharing data to improve treatments is very important for future patients," says Dr. Paul Elbers, intensivist at Amsterdam UMC and project leader. "And if done with meticulous care, this has a strong support base," adds his colleague Dr. Patrick Thorat. In the Netherlands, intensivists from Radboudumc Nijmegen, Erasmus MC Rotterdam, OLVG Amsterdam, UMC Utrecht, and Maastricht UMC+ support this initiative. They also intend to share patient data in this responsible way. And the patient organisations IC connect as well as the foundation for Family Centered Intensive Care support this type of data sharing. "Previously, only anonymised data from American intensive care units were freely available. However, intensive care organisation and type of patients may be quite different between the USA and Europe. This might result in inappropriate algorithms. That is why this European initiative as well as worldwide collaboration are so important," says Dr. Thorat.

Privacy guaranteed

Patient privacy is a top priority for Amsterdam UMC, ESICM and NVIC. It goes without saying that all laws and regulations are strictly respected. In Amsterdam UMC, patients can always choose to opt out of their data being used for scientific research; Data from such patients will not be released. In addition, access is only granted to doctors and scientists that fulfill strict criteria and who sign an agreement. The data can only be used

for scientific research and have been thoroughly and carefully de-identified to the extent that it is not reasonably likely that data subjects are identifiable in the context of the General Data Protection Regulation (GDPR). This has been verified by independent experts led by Prof. Eric Sijbrands, a privacy expert at the Netherlands Federation of University Medical Centers (NFU).

Ethics audit

Amsterdam UMC also commissioned an ethics audit by external experts. This was led by clinical ethicist Dr. Erwin Kompanje from Erasmus MC Rotterdam. He is specialised in ethical challenges in intensive care medicine. The assessment concluded that responsible sharing of patient data should be encouraged. Risks have been minimized and this initiative offers hope and perspective for future patients.

Further information

The data are contained in the AmsterdamUMCdb database which contains almost 1 billion clinical observations and medication records from over twenty thousand patients and has been made available through EASY: This is a portal for DANS, the archiving system for permanent access to research data from the Royal Dutch Academy of Sciences (KNAW) and the Dutch Research Council (NWO). Further information about AmsterdamUMCdb may be found at amsterdammedicaldatascience.nl.

For editors (not for publication)

Amsterdam UMC, the ESICM and the NVIC encourage public debate on sharing data responsibly for the benefit of the care and treatment of future patients. Please contact Nicole de Haan, scientific information officer at the Amsterdam UMC communication department for further information or interview requests at should you require any further information. They may be reached at +31-20-4443444 or mobile +31-6-41859331 or by e-mail at n.a.a.dehaan@amsterdamumc.nl. A full list of available persons may be found below.

Access to the AmsterdamUMCdb database for scientific research may be granted upon request. This requires proof of completion of a course on data integrity, the name of a respected health care professional or researcher from the intensive care community that supports the request and signing an end user agreement.

This press release is available in multiple languages through amsterdammedicaldatascience.nl

List of available contact persons

Project leaders

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Privacy expert

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Representative for patients

Dr. Lilian Vloet, PhD (Dutch, English), Chair IC Connect Patient Association; Chair Family Centered Intensive Care Foundation; Professor acute intensive care, HAN University of Applied Sciences.

ESICM leadership

Prof. dr. Joseph Kesecioglu, MD, PhD (Turkish, English, Dutch), ESICM president; Intensivist and chair of the department of intensive care medicine, UMC Utrecht; **Prof. dr. Armand Girbes, MD, PhD** (Dutch, French, English, German), Chairman of the Division of Scientific Affairs, ESICM; Intensivist, clinical pharmacologist and chairman of the department of intensive care medicine, Amsterdam UMC; **Prof. dr. Maurizio Cecconi, MD, PhD** (Italian, English), ESICM president elect; Intensivist and chair of the department of intensive care medicine, Humanitas Milano; **Dr. Ari Ercole** (English, German, Italian), Chair of the ESICM data science section; intensivist, Cambridge University.

NVIC leadership

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Amsterdam UMC leadership

Prof. dr. Mark Kramer, MD, PhD (Dutch, English), Member of the executive board and internist, Amsterdam UMC; **Prof. dr. Armand Girbes, MD, PhD** (Dutch, French, English, German), Intensivist, clinical pharmacologist and chairman of the department of intensive care medicine, Amsterdam UMC; Chairman of the Division of Scientific Affairs, ESICM.

Representatives for supporting hospitals

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