

本新闻稿由以下机构联合发布

- Amsterdam UMC (阿姆斯特丹大学医学中心)
- ESICM (欧洲重症医学协会)
- NVIC (荷兰重症医学协会)



Amsterdam UMC对外开放ICU患者数据以促进科研为挽救更多患者

Amsterdam UMC是欧洲第一家为促进科研及改善医疗照护而对外开放ICU患者匿名数据的医院。根据数据中所含信息基本无法追溯到患者个人身份。数据包含总计将近10亿条记录，其主要收集于医学监控仪器。利用这些大数据，全世界各地的医生和科研人员都可以通过人工智能技术研发算法，从而协助为未来的ICU患者提供更及时、准确的治疗服务。这是一项迫在眉睫的挑战，因为ICU患者的死亡率仍然高达30%，这意味着在欧洲每天都有数百人死亡。

欧洲倡议

ESICM在设立数据科学部之际同时发起了数据共享的倡议。该倡议首先得到NVIC的支持，ESICM亦鼓励其他医院效仿。Amsterdam UMC的重症医学专家兼项目负责人Paul Elbers博士说：“数据共享对于今后改善临床治疗非常重要”。他的同事Patrick Thorat博士补充道：“如果实施得当的话，这类举措其实有很广泛的支持”。在荷兰，来自Radboudumc Nijmegen、Erasmus MC Rotterdam、OLVG Amsterdam、UMC Utrecht及Maastricht UMC+的重症医学专家均支持这一倡议，他们亦表示有意负责其数据共享的计划。以前，只有美国有对外开放的ICU数据库。“但是美国和欧洲的重症监护管理以及患者人群类型差异可能非常大，基于前者所建立的方法或许并不适用于后者。因此，该欧洲倡议乃至全球范围的合作是十分重要的”，Thorat博士说道。

隐私保障

对Amsterdam UMC、ESICM和NVIC而言，保护患者隐私是重中之重，更毋用论所有的法律法规都对此有所规定。在Amsterdam UMC，患者可以选择授权其数据被用于科学研究，这类患者的数据亦不会被公开。此外，只有严格符合标准并签署协议的医生和科研人员才能获得数据访问权限。这些数据只用于科学研究，且已在《通用数据保护条例》(GDPR)的要求范围内彻底、仔细地患者个人信息去除，从而确保数据主体不再能被识别。由荷兰大学医学中心联盟(NFU)的隐私事务专家Eric Sijbrands教授所领导的独立专家团已对此进行了确认。

伦理审查

Amsterdam UMC也委托进行了独立的伦理审查，由Erasmus MC Rotterdam的临床伦理学专家Erwin Kompanje博士所领导，其专门研究在ICU中的伦理问题。评估结果鼓励数据在有责可问的情况下共享，且该计划已将风险降至最低，为将来的患者治疗带来了希望和前景。

更多信息

数据存放于AmsterdamUMCdb数据库，其包含来自2万多名患者的将近10亿条临床观察结果和用药记录，并已通过EASY系统发布。EASY是DANS的一项用于科研数据存档的服务，归属于荷兰皇家科学院(KNAW)和荷兰研究委员会(NWO)。关于获取AmsterdamUMCdb访问权限、数据库详情等事宜，请访问：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For editors (not for publication)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

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Representative for patients

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NVIC leadership

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