

Gezamenlijk persbericht van

- Amsterdam UMC
- de Europese Vereniging voor Intensive Care Geneeskunde (ESICM)
- de Nederlandse Vereniging voor Intensive Care (NVIC)



Amsterdam UMC stelt data over intensive care patiënten beschikbaar om levens te redden

Als eerste ziekenhuis in Europa stelt Amsterdam UMC data over intensive care patiënten beschikbaar voor wetenschappelijk onderzoek en om de zorg te verbeteren. Individuele patiënten zijn hierbij redelijkerwijs niet identificeerbaar. In totaal zijn er bijna 1 miljard datapunten beschikbaar, vooral vanuit de bewakingsapparatuur. Juist door deze big data kunnen artsen en wetenschappers vanuit de hele wereld algoritmes ontwikkelen met kunstmatige-intelligentie-technieken zoals machine learning. Die moeten zorgen dat toekomstige intensive care patiënten sneller de juiste behandeling krijgen. En dat is hard nodig, want nog steeds komt tot dertig procent van intensive care patiënten te overlijden. Voor Europa betekent dat honderden doden per dag.

Europees initiatief

Het initiatief voor deze ontwikkeling komt van de Europese Vereniging voor Intensive Care Geneeskunde (ESICM) met de oprichting van hun sectie Data Science en wordt gesteund door de Nederlandse Vereniging voor Intensive Care (NVIC). Zij moedigen andere ziekenhuizen aan dit voorbeeld te volgen. "Gegevens delen om behandelingen beter te maken is erg belangrijk voor toekomstige patiënten", aldus dr. Paul Elbers, intensivist in Amsterdam UMC en projectleider. "En als je dat zeer zorgvuldig doet, is daar veel draagvlak voor", vult zijn collega Patrick Thoral aan. In eigen land steunen intensivisten uit Radboudumc Nijmegen, Erasmus MC Rotterdam, OLVG Amsterdam, UMC Utrecht en Maastricht UMC+ het initiatief. Ook zij willen data op deze verantwoorde manier beschikbaar stellen. En ook de patiëntenorganisatie IC connect en de stichting Family Centered Intensive Care laten weten achter deze manier van data delen te staan. "Eerder waren dergelijke gegevens alleen van Amerikaanse intensive cares beschikbaar. Maar de organisatie van intensive care geneeskunde en het type patiënten kunnen flink verschillen tussen de Verenigde Staten en Europa. Dat zou kunnen leiden tot verkeerde algoritmes. Daarom is dit Europese initiatief en wereldwijde samenwerking zo belangrijk", aldus Thoral.

Privacy gewaarborgd

Voor Amsterdam UMC, de ESICM en de NVIC is het waarborgen van de privacy van patiënten van het allergrootste belang. Het spreekt voor zich dat alle wet- en regelgeving hierover strikt wordt nageleefd. In Amsterdam UMC kunnen patiënten altijd bezwaar maken tegen het gebruik van hun gegevens voor wetenschappelijk onderzoek. De

gegevens van de patiënten die bezwaar hebben gemaakt zijn dan ook niet opgenomen in de data die beschikbaar worden gesteld. Bovendien krijgen alleen artsen en wetenschappers die aan strikte eisen voldoen en een overeenkomst tekenen toegang tot de data. De gegevens mogen alleen worden gebruikt voor wetenschappelijk onderzoek en zijn grondig gede-identificeerd. Zo grondig dat de betrokkenen redelijkerwijs niet meer identificeerbaar zijn in de context van de Europese Algemene Verordening Gegevensbescherming (AVG). Dat is gecontroleerd door onafhankelijke experts, onder aanvoering van prof. dr. Eric Sijbrands, privacy deskundige bij de Nederlandse Federatie van Universiteiten (NFU).

Ethische toets

Amsterdam UMC heeft dit initiatief ook ethisch laten toetsen door externe experts. Dit gebeurde onder leiding van klinisch ethicus dr. Erwin Kompanje, verbonden aan het Erasmus MC Rotterdam en gespecialiseerd in ethische vraagstukken rondom intensive care geneeskunde. Eventuele risico's zijn volgens Kompanje geminimaliseerd en het initiatief biedt veel hoop voor toekomstige patiënten. Het delen van gegevens op deze manier is volgens de experts verantwoord en mag worden aangemoedigd.

Meer informatie

De data staan in de AmsterdamUMCdb database. Die bevat bijna 1 miljard klinische observaties en medicatiegegevens over meer dan twintigduizend patiënten en is beschikbaar via EASY. Dat is een afgeschermd portal van het online archiveringssysteem DANS, een instituut voor digitale onderzoeksgegevens van KNAW en NWO. Meer informatie over AmsterdamUMCdb is te vinden op amsterdammedicaldatascience.nl.

Voor redacties (niet voor publicatie)

Amsterdam UMC, de ESICM en de NVIC moedigen het publieke debat aan over het verantwoord delen van gegevens om de behandeling en zorg van toekomstige patiënten te verbeteren. Neem voor meer informatie of interviews met betrokkenen contact op met Nicole de Haan, wetenschapsvoorlichter van de dienst communicatie van Amsterdam UMC op telefoonnummer 020-4443444 of mobiel 06-41859331 en per e-mail via n.a.a.dehaan@amsterdamumc.nl. Een volledige lijst van beschikbare personen vindt u hieronder.

Toegang tot de AmsterdamUMCdb database voor wetenschappelijk onderzoek wordt verleend nadat een aanvraag daartoe is goedgekeurd. Goedkeuring vereist bewijs dat onderwijs is gevolgd over integer omgaan met gegevens, dat een gerespecteerde zorgprofessional of onderzoeker uit de intensive care gemeenschap referent is van de aanvrager en dat een overeenkomst wordt getekend.

Dit persbericht is in meerdere talen beschikbaar via amsterdammedicaldatascience.nl

List of available contact persons

Project leaders

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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.

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Gemeinsame Pressemitteilung von

- Amsterdam UMC
- Europäische Gesellschaft für Intensivmedizin (ESICM)
- Niederländische Gesellschaft für Intensivmedizin (NVIC)



Amsterdam UMC macht anonymisierte Daten von Intensivpatienten frei zugänglich, um Leben zu retten

Als erstes Krankenhaus in Europa macht Amsterdam UMC anonymisierte Patientendaten für Forschung und zur Verbesserung des Gesundheitswesens zugänglich. Es ist nach allgemeinem Ermessen unwahrscheinlich, dass einzelne Patienten anhand dieser Daten identifiziert werden können. Insgesamt sind fast eine Milliarde Datenpunkte verfügbar, meist von angeschlossenen Überwachungsgeräten. Mit dieser großen Menge an Daten (big data) können Ärzte und Wissenschaftler aus der ganzen Welt mit Künstlicher Intelligenz Technologie (KI) wie zum Beispiel Machine Learning Algorithmen entwickeln. Das soll helfen, dass Intensivpatienten in der Zukunft schneller die richtige Behandlung bekommen. Und das ist dringend nötig: noch immer sterben bis zu 30% der Patienten auf einer Intensivstation. Das bedeutet Hunderte Tote in Europa jeden Tag.

Europäische Initiative

Diese Entwicklung wurde von der Europäischen Vereinigung für Intensivmedizin (ESICM) mit der Gründung ihrer Data Science-Sektion initiiert und wird unterstützt durch die Niederländische Vereinigung für Intensivmedizin (NVIC). Sie ermutigen andere Krankenhäuser, diesem Beispiel zu folgen. "Daten miteinander teilen, um Behandlungen besser zu machen, ist sehr wichtig für unser zukünftigen Patienten." so Dr. Paul Elbers, Intensivmediziner im Amsterdam UMC und Projektleiter. "Und wenn man das sehr vorsichtig macht, gibt es hier auch viel Unterstützung für," ergänzt sein Kollege Dr. Patrick Thoral. In den Niederlanden unterstützen Intensivmediziner von Radboudumc Nijmegen, Erasmus MC Rotterdam, OLVG Amsterdam, UMC Utrecht und Maastricht UMC+ die Initiative. Auch diese Kliniken wollen Daten auf diese verantwortungsbewusste Art und Weise verfügbar machen. Auch die Patientenvereinigung IC connect und die Stiftung Family Centered Intensive Care stehen hinter dieser Art und Weise der Weitergabe von Daten. "Bis jetzt sind nur anonymisierte Daten aus amerikanischen Intensivstationen frei zugänglich. Aber Intensivmedizin ist in den USA häufig anders organisiert und auch die behandelten Patienten können anders sein. Das kann zu ungeeigneten Algorithmen führen. Darum ist diese europäische Initiative und eine weltweite Zusammenarbeit so wichtig," sagt Dr. Thoral.

Datenschutz garantiert

Für Amsterdam UMC, ESICM und die NVIC ist das Garantieren von Datenschutz für Patienten von allergrößter Wichtigkeit. Es ist selbstverständlich, dass alle Gesetze und

Regeln hierzu strikt eingehalten werden. In Amsterdam UMC können Patienten jederzeit angeben, dass ihre Daten nicht für wissenschaftliche Forschung verwendet werden sollen; Daten von solchen Patienten werden nicht freigegeben. Außerdem erhalten nur Ärzte und Wissenschaftler die strikte Kriterien erfüllen und einen Vertrag unterschreiben Zugang zu den Daten. Die Daten dürfen nur für wissenschaftliche Forschungszwecke genutzt werden und sind gründlich und sorgfältig desidentifiziert, so dass Personen konform der Europäischen Datenschutzverordnung (GDPR) nach allgemeinem Ermessen nicht identifiziert werden können. Das ist durch unabhängige Experten unter Leitung von Prof. Eric Sijbrands, Datenschutzexperte bei der Niederländischen Vereinigung von Universitäten (NFU).

Ethische Prüfung

Amsterdam UMC hat auch eine externe, unabhängige ethische Prüfung in Auftrag gegeben. Diese fand statt unter Leitung von Dr. Erwin Kompanje, Erasmus MC Rotterdam. Er ist spezialisiert auf ethische Probleme in der Intensivmedizin. Die Prüfung zeigte, dass zu verantwortungsbewusstem Teilen von Patientendaten ermutigt werden sollte. Risiken sind minimalisiert und diese Initiative bietet viel Hoffnung und Perspektive für zukünftige Patienten.

Mehr Information

AmsterdamUMCdb enthält fast 1 Milliarde klinische Beobachtungen und Medikamentendaten von mehr als 20.000 Patienten und wird verfügbar gemacht über EASY. Das ist ein Portal des Online-Archivierungssystems DANS von der königlichen Akademie der Wissenschaften (KNAW) und des Niederländischen Forschungsrates (NWO) für dauerhaften Zugang zu digitalen Forschungsdaten. Alle Informationen zu Zugang, Datenstruktur und Inhalt von AmsterdamUMCdb sind zu finden auf amsterdammedicaldatascience.nl.

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Communiqué de presse commun de

- Amsterdam UMC
- La Société Européenne des Soins Intensifs (ESICM)
- La Société Néerlandaise des Soins Intensifs (NVIC)



Amsterdam UMC met à disposition des données sur les patients en soins intensifs pour sauver des vies.

Amsterdam UMC est le premier hôpital en Europe à rendre les données des patients, traités en soins intensifs, disponibles pour la recherche et l'amélioration des soins. Il n'est pas raisonnablement probable que chaque patient puisse être identifié à partir de ces données. Au total, près d'un milliard de points de données sont disponibles provenant principalement de l'équipement de surveillance connecté. Grâce à ces données massives ('big data'), des médecins et des scientifiques du monde entier pourront développer des algorithmes faisant appel à des techniques d'intelligence artificielle telles que l'apprentissage automatique. Ces techniques doivent veiller à ce que les futurs patients en soins intensifs reçoivent le traitement approprié plus rapidement. Il s'agit d'un défi urgent, car jusqu'à 30 % des patients en soins intensifs meurent encore. Cela représente des centaines de morts en Europe chaque jour.

Initiative européenne

Ce développement a été lancé par la Société Européenne pour la Médecine de Soins Intensifs (European Society of Intensive Care Medicine - ESICM) avec la création de sa section de Science des Données (Data Science) et est soutenue par l'Association Néerlandaise pour les Soins Intensifs (NVIC). Ils encouragent d'autres hôpitaux à suivre cet exemple. « Le partage des données pour améliorer les traitements est très important pour les futurs patients », a déclaré le Dr Paul Elbers, intensiviste-réanimateur à l'UMC d'Amsterdam et chef de projet. Son collègue Patrick Thoral ajoute: « Si vous le faites méticuleusement, cela suscite un vif soutien ». Aux Pays-Bas, des intensivistes-réanimateurs de Radboudumc Nijmegen, Erasmus MC Rotterdam, OLVG Amsterdam, UMC Utrecht et Maastricht UMC+ soutiennent cette initiative. Ils souhaitent également rendre les données disponibles de manière responsable. De plus, l'organisation de patients aux soins intensifs "IC connect" et la fondation de soins intensifs centrés sur la famille (Family Centered Intensive Care) leur ont fait savoir leur support pour le partage des données des patients anonymisées de cette façon. "Auparavant, seules les données des patients aux soins intensifs américains étaient librement disponibles. Mais l'organisation des soins intensifs et les services de réanimation ainsi que le type de patients peuvent varier considérablement entre les États-Unis et l'Europe. Cela pourrait mener à des algorithmes inappropriés. C'est pourquoi cette initiative européenne et cette coopération mondiale sont si importantes", a déclaré le Dr. Thoral.

Protection des données garantie

La protection de la vie privée des patients est une priorité absolue pour Amsterdam UMC, l'ESICM et la NVIC. Il va sans dire que toutes les lois et tous les règlements sont strictement respectés. À Amsterdam UMC les patients peuvent toujours choisir de ne pas permettre l'utilisation de leurs données pour la recherche scientifique. Les données de ces patients ne seront pas publiées. En plus, l'accès à ces données n'est autorisé qu'aux médecins et scientifiques répondant à des critères stricts et signant un accord. Les données ne peuvent être utilisées que pour des recherches scientifiques et ont été soigneusement et complètement dé-identifiées dans une mesure où il est raisonnablement peu probable que les personnes concernées soient identifiables dans le contexte du règlement général européen sur la protection des données (RGPD). Cela a été vérifié par des experts indépendants, dirigés par le Pr. Eric Sijbrands, expert en protection de la vie privée à la Fédération Néerlandaise des Centres Hospitaliers Universitaires (NFU).

Test éthique

Amsterdam UMC a également commandé un audit éthique par des experts externes. Le Dr Erwin Kompanje, éthicien clinique affilié à Erasmus MC Rotterdam a dirigé cette étude. Il est spécialisé dans les questions éthiques liées à la médecine de soins intensifs. L'évaluation a conclu que le partage responsable des données des patients devrait être encouragé. Les risques ont été minimisés et cette initiative offre espoir et perspective aux futurs patients.

Plus d'informations

Les données figurent dans la base de données AmsterdamUMCdb, qui contient près d'un milliard d'observations cliniques et de données sur les médicaments de plus de vingt mille patients. Elle est disponible via EASY. Ceci est un portail du système d'archivage permettant un accès permanent aux données de recherche de l'Académie Royale Néerlandaise des Sciences (KNAW) et le Conseil Néerlandais de la Recherche (NWO). Pour plus d'informations sur AmsterdamUMCdb, visitez le site amsterdammedicaldatascience.nl.

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Comunicado de prensa conjunto de

- Amsterdam UMC
- Asociación Europea para la Medicina de Cuidados Intensivos (ESICM)
- Asociación Holandesa de cuidados intensivos (NVIC)



Amsterdam UMC pone a disposición pública los datos de pacientes en cuidados intensivos para salvar vidas

El Consorcio de Hospitales Universitarios de Amsterdam (Amsterdam UMC) es el primero en Europa en hacer disponibles los datos de pacientes que han estado hospitalizados en la unidad de cuidados intensivos para la investigación y mejorar los servicios de salud. Al hacerlo, los pacientes individuales no son razonablemente identificables. Casi mil millones de puntos de datos estarán disponibles en total, la mayoría de ellos proviene del equipo de monitoreo. Gracias a esta gran cantidad de datos (Big Data), los médicos e investigadores de todo el mundo podrán desarrollar algoritmos con técnicas de inteligencia artificial como aprendizaje automático (Machine Learning). Estas técnicas garantizarán que futuros pacientes en la unidad de cuidados intensivos reciban un tratamiento adecuado y aún más rápido que hasta ahora. Y esto es absolutamente necesario puesto que actualmente el 30% de los pacientes admitidos en la unidad de cuidados intensivos mueren aun recibiendo cuidados médicos óptimos. Eso significa cientos de muertos en Europa cada día.

Iniciativa europea

Este proyecto fue iniciado por la Asociación Europea para la Medicina de Cuidados Intensivos (European Society of Intensive Care Medicine - ESICM) con el establecimiento de su sección de Data Science y cuenta con el apoyo de la asociación Holandesa de cuidados intensivos (NVIC). Ambos esperan animar otros hospitales a seguir este ejemplo. “Compartir datos para mejorar los tratamientos es importante para futuros pacientes”, dice el Dr. Paul Elbers, intensivista en el Amsterdam UMC y director del proyecto. Su colega el Dr. Patrick Thorat agrega: “Y si lo haces meticulosamente, hay mucho apoyo para ello”. En los Países Bajos, los intensivistas del Radboudumc Nijmegen, Erasmus MC Rotterdam, OLVG Amsterdam, UMC Utrecht y Maastricht UMC+ apoyan el proyecto. Ellos también quieren compartir sus datos de esta manera responsable. Además, la organización de pacientes en cuidados intensivos (IC connect) y la Fundación Cuidados Intensivos Centrados en la Familia (Family Centered Intensive Care) hacen saber que ofrecen su apoyo al intercambio responsable de datos de esta manera. “Anteriormente, solo los datos de cuidados intensivos en los Estados Unidos de Norte América estaban disponibles libremente. Sin embargo, la organización y el tipo de pacientes pueden variar considerablemente entre los Estados Unidos y Europa. Eso podría resultar en algoritmos erróneos. Por ello, esta iniciativa europea y la cooperación global son tan importante”, dice Thorat.

Privacidad garantizada

Para Amsterdam UMC, el ESICM y el NVIC, la protección de la privacidad de los pacientes es de suma importancia. No hace falta decir que todas las leyes y reglamentos son respetados estrictamente. En el Amsterdam UMC, los pacientes siempre pueden oponerse al uso de sus datos para las investigaciones científicas. Entonces, los datos de estos pacientes no estarán en la base de datos. Encima, solo los médicos e investigadores que cumplen requisitos estrictos y que firman un acuerdo de confidencialidad pueden acceder a los datos. Se puede usar los datos exclusivamente para las investigaciones, y todos los datos son exhaustivamente anonimizados. Tan exhaustivamente que los pacientes ya no pueden ser identificados razonablemente en el contexto del Reglamento General de Protección de Datos (RGPD). Todo esto ha sido verificado por expertos independientes, organismo encabezado por el Prof. Dr. Eric Sijbrands, profesor de medicina interna en el Erasmus MC Rotterdam y experto en privacidad en la Federación Holandesa de Universidades (Netherlands Federation of University Medical Centres).

Aprobación por el comité de ética

El Amsterdam UMC también ha expuesto su protocolo a prueba ante un comité de ética independiente. Esto se realizó bajo la dirección del ético clínico Dr. Erwin Kompanje, afiliado al Erasmus MC Rotterdam y especializado en cuestiones éticas relacionadas con la medicina de cuidados intensivos. Según Kompanje, los riesgos potenciales se ha minimizado y la iniciativa ofrece mucha esperanza para futuros pacientes. Los expertos consideran que el intercambio de los datos de esta manera está justificado y se puede alentar.

Más información

Los datos que se publica estarán en la base de datos AmsterdamUMCdb. Esta base contiene casi mil millones de observaciones clínicas y datos de medicamentos de más de veinte mil pacientes y está disponible a través de EASY. Esto es un portal del sistema de archivo en línea DANS, del KNAW y NWO para acceso permanente a los datos de investigación digital. Usted puede encontrar más información sobre AmsterdamUMCdb en 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.

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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。

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