

What initiatives are ongoing to help patients gain access to healthcare data in journals?

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Patients' access to healthcare data

- Why is it important?
- What data?
- Barriers to access
- Initiatives
- Conclusion

Why is patient access important?

- More-engaged patients have lower costs and better health outcomes
- Improves quality
- Improves patient satisfaction

“Getting access to personal health information is the start of engaging patients to be full partners in their care” Lygeia Ricciardi, director of the Office of Consumer eHealth (National Coordinator for Health Information Technology)

...[When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients. We must make this the new gold standard of healthcare quality and the ultimate goal of all our improvement efforts:

Not better hospitals.

Not better physician practices.

Not more sophisticated electronic medical systems.

Happier, healthier patients.

—Charles Safran

What data?

- Personal medical health records
 - Access to personal medical data allows patients to manage their own health
 - The aim is to move patients and doctors into a relationship of “shared accountability”
- Healthcare data published in journals
 - Access to published healthcare data allows patients to stay on top of chronic conditions

Barriers to access

- Awareness
- Jargon/understanding
- Paywalls
- Technology (mobile apps, enhanced articles etc.)

Initiatives

- *patient*ACCESS
- *patient*INFORM
- Access to Research
- Open access journals
- Journal-specific initiatives

*patient*ACCESS

- Provides patients and their caregivers with low-cost access to peer-reviewed research articles
- *patient*ACCESS is a collaborative project with selected publishers such as Wiley, the Professional/Scholarly Publishing (PSP) Division of the Association of American Publishers, the International Association of Scientific, Technical & Medical Publishers (STM), and the Copyright Clearance Center (CCC).
- Articles in included journals can be obtained by patients via RightsLink (there is a fee of \$3.5 + taxes levied by CCC). Articles are then emailed to the requestor.

*patient*INFORM

- Publishers who participate in *patient*INFORM help patients gain access to research in two ways:
 - By allowing participating health organizations that create research summaries, news reports etc. to place special links on their sites to the associated research articles in participating journals. These links provide users with free access to the articles.
 - By providing patients and their caregivers with free or reduced-price access to relevant articles through their own web sites.

patient **INFORM**

ACCESS + INTERPRETATION = UNDERSTANDING + EMPOWERMENT



FROM THE WORLD'S LEADING PUBLISHERS...



MASSACHUSETTS MEDICAL SOCIETY



patient **INFORM**

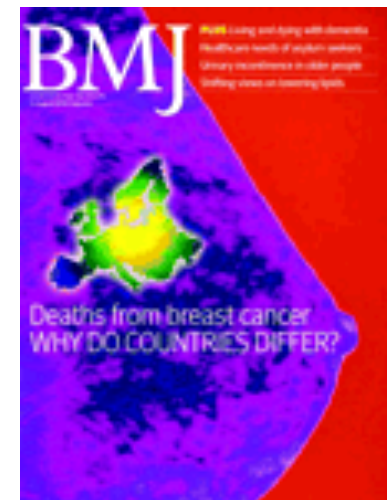
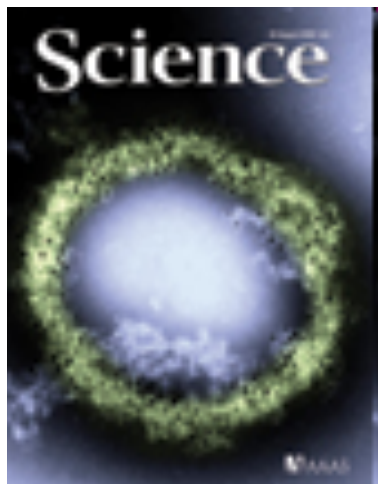
ACCESS + INTERPRETATION = UNDERSTANDING + EMPOWERMENT

THE LANCET

"Introduction of rotavirus vaccines for African children, along with imminent introduction of pneumococcal and meningococcal conjugate vaccines in parts of Africa, could inaugurate a new era of reduction of childhood disease and mortality."



PROVIDING ACCESS TO THE TOP MEDICAL JOURNALS...



patient **INFORM**

ACCESS + INTERPRETATION = UNDERSTANDING + EMPOWERMENT

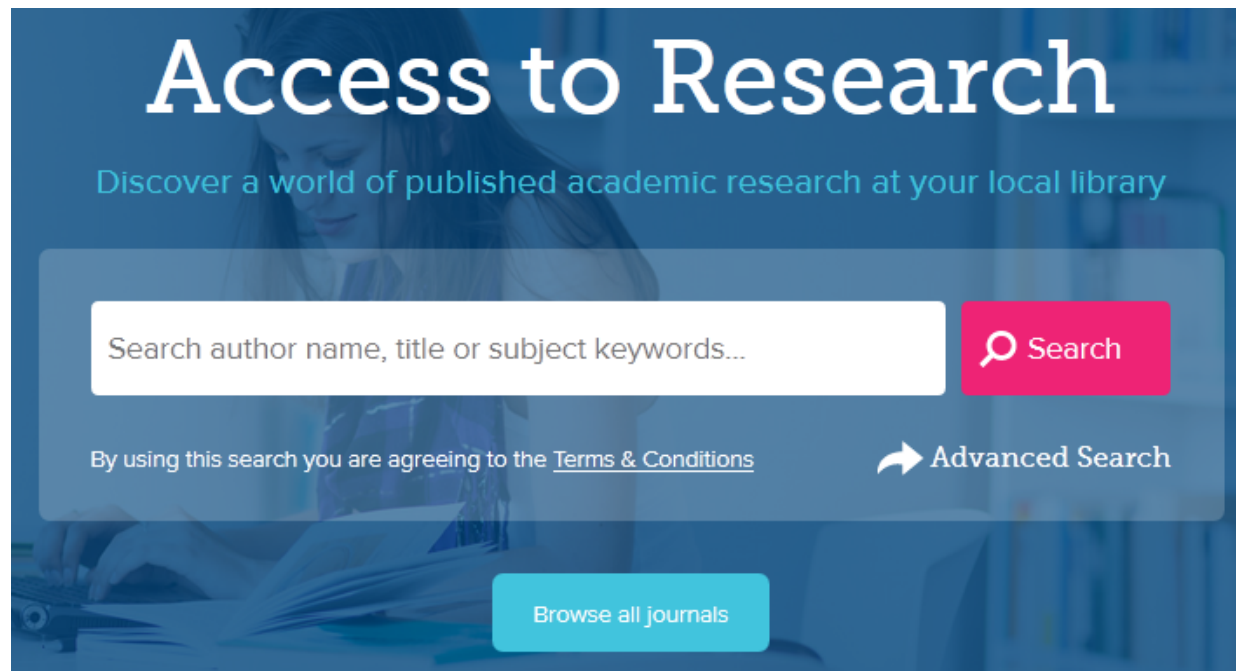


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Access to Research

- Gives free, walk-in access to a wide range of academic articles and research in participating public libraries across the UK
- > 8,400 journals included in the service (Jan 2014). As more publishers continue to join the initiative, even more content will become freely available.



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Open access journals



- Universally available online without any barriers to access
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- Immediate publication
- Users are free to read, download, copy, distribute, print, search, or link to the full texts of these articles for any (non-commercial) purpose
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- Supported by publication fees

Some open access journals

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- [Pragmatic and Observational Research](#)
- [Smart Homecare Technology and TeleHealth](#)

Journal-specific initiatives



- Enhanced papers (videos, podcasts)
- Lay summaries
- BMJ
- JAMA

Journal-specific initiatives


- Enhanced papers (video abstracts, podcasts)

Back to Dovepress Journal: [Vascular Health and Risk Management](#)

Effect of melatonin on nocturnal blood pressure: meta-analysis of randomized controlled trials

 Metrics  Altmetric 1

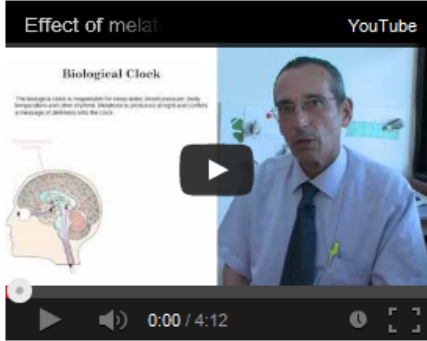
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Effect of melatonin on nocturnal blood pressure: meta-analysis of randomized controlled trials

Biological Clock

The biological clock is responsible for many vital functions, including sleep, feeding, and reproduction. It is a complex system that regulates the timing of many biological processes. Melatonin is a hormone that is produced at night and helps to regulate the biological clock.

0:00 / 4:12

Video abstract presented by Ehud Grossman
Views: 2992

Background: Patients with nocturnal hypertension are at higher risk for cardiovascular complications such as myocardial infarction and cerebrovascular insult. Published studies inconsistently reported decreases in nocturnal blood pressure with melatonin.

Methods: A meta-analysis of the efficacy and safety of exogenous melatonin in ameliorating nocturnal blood pressure was performed using a random effects model of all studies fitting the inclusion criteria, with subgroup analysis of fast-release versus controlled-release preparations.

BMJ Select journal

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| | BMJ talk medicine – Apophyseal injury in children and adolescents | ▶ 1,687 |
| | BMJ talk medicine – Excess weight gain in the first 18 months and later childhood weight and arterial wall thickness | ▶ 48 |
| | BMJ talk medicine – Characterisation of faecal protease activity in irritable bowel syndrome with diarrhoea | ▶ 359 |
| | BMJ talk medicine – In this issue: June 2014 | ▶ 267 |
| | BMJ talk medicine – Drugs for weight loss | ▶ 3,290 |

Journal-specific initiatives

Red Blood Cell Transfusion and Mortality in Trauma Patients

- Lay summary

Article Source:

[Red Blood Cell Transfusion and Mortality in Trauma Patients: Risk-Stratified Analysis of an Observational Study](#)

Perel P, Clayton T, Altman DG, Croft P, Douglas I, et al. (2014) Red Blood Cell Transfusion and Mortality in Trauma Patients: Risk-Stratified Analysis of an Observational Study. *PLoS Med* 11(6): e1001664. doi: 10.1371/journal.pmed.1001664

Editors' Summary

Background. Trauma—a serious injury to the body caused by violence or an accident—is a major global health problem. Every year, injuries caused by traffic collisions, falls, blows, and other traumatic events kill more than 5 million people (9% of annual global deaths). Indeed, for people between the ages of 5 and 44 years, injuries are among the top three causes of death in many countries. Trauma sometimes kills people through physical damage to the brain and other internal organs, but hemorrhage (serious uncontrolled bleeding) is responsible for 30%–40% of trauma-related deaths. Consequently, early trauma care focuses on minimizing hemorrhage (for example, by using compression to stop bleeding) and on restoring blood circulation after blood loss (health-care professionals refer to this as resuscitation). Red blood cell (RBC) transfusion is often used for the management of patients with trauma who are bleeding; other resuscitation products include isotonic saline and solutions of human blood proteins.

Why Was This Study Done? Although RBC transfusion can save the lives of patients with trauma who are bleeding, there is considerable uncertainty regarding the balance of risks and benefits associated with this procedure. RBC transfusion, which is an expensive intervention, is associated with several potential adverse effects, including allergic reactions and infections. Moreover, blood supplies are limited, and the risks from transfusion are high in low- and middle-income countries, where most trauma-related deaths occur. In this study, which is a secondary analysis of data from a trial (CRASH-2) that evaluated the effect of tranexamic acid (which stops excessive bleeding) in patients with trauma, the researchers test the hypothesis that RBC transfusion may have a beneficial effect among patients at high risk of death following trauma but a harmful effect among those at low risk of death.

What Did the Researchers Do and Find? The CRASH-2 trial included 20,127 patients with trauma and major bleeding treated in 274 hospitals in 40 countries. In their risk-stratified analysis, the researchers investigated the effect of RBC transfusion on CRASH-2 participants with a predicted risk of death (estimated using a validated model that included clinical variables such as heart rate and blood pressure) on admission to hospital of less than 6%, 6%–20%, 21%–50%, or more than 50%. That is, the researchers compared death rates among patients in each stratum of predicted risk of death who received a RBC transfusion with death rates among patients who did not receive a transfusion. Half the patients received at least one transfusion. Transfusion was associated with an increase in all-cause mortality at 28 days after trauma among patients with a predicted risk of death of less than 6% or of 6%–20%, but with a decrease in all-cause mortality among patients with a predicted risk of death of more than 50%. In absolute figures,

compared to no transfusion, RBC transfusion was associated with 5.1 more deaths per 100 patients in the patient group with the lowest predicted risk of death but with 11.9 fewer deaths per 100 patients in the group with the highest predicted risk of death.

What Do These Findings Mean? These findings show that RBC transfusion is associated with an increase in all-cause deaths among patients with trauma and major bleeding with a low predicted risk of death, but with a reduction in all-cause deaths among patients with a high predicted risk of death. In other words, these findings suggest that the effect of RBC transfusion on all-cause mortality may vary according to whether a patient with trauma has a high or low predicted risk of death. However, because the participants in the CRASH-2 trial were not randomly assigned to receive a RBC transfusion, it is not possible to conclude that receiving a RBC transfusion actually increased the death rate among patients with a low predicted risk of death. It might be that the patients with this level of predicted risk of death who received a transfusion shared other unknown characteristics (confounders) that were actually responsible for their increased death rate. Thus, to provide better guidance for clinicians caring for patients with trauma and hemorrhage, the hypothesis that RBC transfusion could be harmful among patients with trauma with a low predicted risk of death should be prospectively evaluated in a randomised controlled trial.

Additional Information. Please access these websites via the online version of this summary at <http://dx.doi.org/10.1371/journal.pmed.1001664>.

- This study is further discussed in a *PLOS Medicine* Perspective by Druin Burch
- The World Health Organization provides information on injuries and on violence and injury prevention (in several languages)
- The US Centers for Disease Control and Prevention has information on injury and violence prevention and control
- The National Trauma Institute, a US-based non-profit organization, provides information about hemorrhage after trauma and personal stories about surviving trauma
- The UK National Health Service Choices website provides information about blood transfusion, including a personal story about transfusion after a serious road accident
- The US National Heart, Lung, and Blood Institute also provides detailed information about blood transfusions
- MedlinePlus provides links to further resources on injuries, bleeding, and blood transfusion (in English and Spanish)
- More information is available about CRASH-2 (in several languages)

Journal-specific initiatives

- BMJ – *Promoting patient partnership*
 - Embedded patient peer review of research papers where patient input is helpful
 - Publish papers that advance the science, implementation and assessment of the impact of patient partnership, shared decision making and patient-centred care
 - Request authors to obtain input from patients and document their contribution
 - Publish patient co-authored “state-of-the-art” reviews
 - Educational articles also peer reviewed by patients
 - Invite expert patients on the Editorial Board
 - Recruit a Patient Editor
 - Encourage patients to participate in internal decision making committees
 - Provide input into lay versions of papers published in the “overdiagnosis” series (Consumer Reports, in partnership with Choosing Wisely initiative)



English

Español

Français

Italiano

中国的

русский

Português

Deutsch

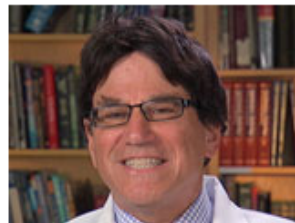
All

Author Interviews — Translations

Summaries of important research published in JAMA Network journals, described by authors in their own words and translated into several languages.



Testing Identifies Genetic Mutations That Can Help Target Lung Cancer Treatment
JAMA. 2014;311(19):1998-2006.



Early Detection and Treatment Still Most Important For Preventing Glaucoma Associated ...
JAMA. 2014;311(18):1901-1911.



Number of American Children with Diabetes Rising
JAMA. 2014;311(17):1778-1786.



New Initiative Gets Clot Dissolving Medications to Stroke Patients Faster
JAMA. 2014;311(16):1632-1640.



Improving Our Understanding of Fibromyalgia
JAMA. 2014;311(15):1547-1555.



New Changes in Blood Pressure Guidelines
JAMA. 2014;311(14):1424-1429.



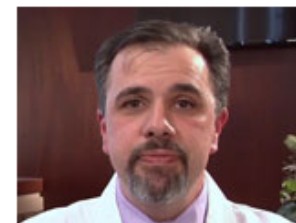
Mammogram Screening Decisions Based on Individual Risk
JAMA. 2014;311(13):1327-1335.



Effects of Web-Based Alcohol Intervention on College Students
JAMA. 2014;311(12):1218-1224.



Critical Illness and Risk of Psychiatric Illness
JAMA. 2014;311(11):1133-1142.



Two Surgeries Help With Common Female Condition
JAMA. 2014;311(10):1023-1034.

Conclusion

- Push towards patients involvement and engagement in healthcare
- More initiatives are being launched to facilitate patients' access to healthcare data
- If you're publishing articles that are relevant to patients as well as experts, it's important that these are published in journals that allow free access or that participate in one of these initiatives

Discuss?

Thank you

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