

patient ACCESS

Meeting the needs of patients
and care givers

Jayne Marks
Wolters Kluwer

Background to the project

- *patientInform* launched 2005
- 12 Health organizations provide patient summaries for original research articles
- Participating publishers provide access to the original article
- Limited in scope and quantity of research covered as the content is hard to create
- Patient advocacy groups asked for wider access to research for patients and care givers

patient **INFORM**

ACCESS + INTERPRETATION = UNDERSTANDING + EMPOWERMENT

patientACCESS is being trialed as a way to meet this need

- **patientACCESS** is an initiative where publishers provide patients and caregivers low or no-cost access to articles from leading medical research journals
- The service has been developed by the CCC using their RightsLink system
- Pilot phase designed to test logistics, refine technology issues, and assess patient interest
- Full launch planned for 2014 when additional publishers will be welcome to join



The pilot sites are being rolled out

- Publishers are responsible for placing the link on their site and the terms of usage of the article
- Patients register to use the service but their details are kept confidential
- Abuse is controlled through monitoring downloads
- Publishers are charged a per download fee
- Users may be charged at the discretion of the publisher (current pilots range from free to \$8)
- ASCO, Sage, AACR and Wiley are live
- Elsevier and Wolters Kluwer plan to roll out in the next few months

- New Users: Please register, then proceed to purchase the article.

Registered Users please login:

- Access your saved publications, articles and search history
- Manage your email alerts, orders and account information
- Change your contact information, including your e-mail address

E-mail:
Password:

Please register to:

- Save publications, articles and search history
- Get email alerts
- Get all the benefits mentioned below!

[Register now >](#)

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Patients and/or caregivers may [access](#) the article in relation to their own personal healthcare as a registered member only. Terms and conditions will apply.

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Title: Acquisition of cytogenetic abnormalities in patients with IPSS defined lower-risk myelodysplastic syndrome is associated with poor prognosis and transformation to acute myelogenous leukemia

Author: Elias Jabbour, Koichi Takahashi, Xuemei Wang, A. Megan Cornelison, Lynne Abruzzo, Tapan Kadia, Gautam Borthakur, Zeev Estrov, Susan O'Brien, Mar Mallo, William Wierda, Sherry Pierce, Yue Wei, Francisco Sole, Rui Chen, Hagop Kantarjian, Guillermo Garcia-Manero

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If you're a [copyright.com](#) user, you can login to RightsLink using your [copyright.com](#) credentials. Already a [RightsLink](#) user or want to [learn more?](#)

Welcome to RightsLink

John Wiley and Sons has partnered with Copyright Clearance Center's RightsLink service to provide access to articles for use by patients and/or their caregivers. This service exists to help people with

User feedback has been positive so far

- The market response has been almost immediate: publishers that have launched patientACCESS have seen orders placed practically from day one
- There has not been any noticeable cannibalization of existing sales
- Pilot publishers so far have seen orders of around 600 articles per month
- Reports are provided to the publisher showing usage



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Barriers that limit access to sometimes critical information relating to latest research about a particular disease or condition are now lowered for those who most need the information. **patientACCESS**, a pilot project, provides patients and caregivers access to the latest scholarly research articles from selected leading medical research journals at low or no cost.

How does *patientACCESS* work? A patient or caregiver finds a useful scholarly journal abstract or reference using online searches. Access to the full non-summarized article is granted through a simple link via RightsLink™ if the journal is included in the pilot project (link to participating journals page). A one-time registration is required that identifies the patient or caregiver and subsequently the full article is emailed to the requestor. The patient or caregiver can then print the article for further study and share the article with a trusted healthcare professional.



The participating publishers are the American Association for Cancer Research (AACR), American Society for Clinical Oncology (ASCO), Elsevier, SAGE, Wiley and Wolters Kluwer Health, and the Copyright Clearance Center (CCC).

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Questions?

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