

Dear Dr Viego, Dr Sanchez, and Dr. Lin,

It has come to our attention that the publication “Enforcing transparent access to private content in social networks by means of automatic sanitization” published in Expert Systems with Applications violated our website's terms of service by obtaining data without permission and publishing an unredacted quote from a patient with HIV who had not consented to share their data with you in this way.

Specifically:

1.) Data was gathered from the logged-in section of PatientsLikeMe from the forums without permission, in violation of our User Agreement (https://www.patientslikeme.com/about/user_agreement) which states:

The Site content, including the Member Area and the content and information contained in the Member Area, is for the personal use of individual members only and may not be used in connection with any commercial endeavors. Organizations, companies, and/or businesses may not become members and should not use the Site without express consent from PatientsLikeMe. Members of PatientsLikeMe with individual commercial interests may not solicit or overtly promote their products or services within the Member Area. All content shared within the site is not for external use. To garner permission and access to members, please direct all media and analyst inquiries to mediarelations@patientslikeme.com and all research requests to research@patientslikeme.com. Representatives from life sciences and insurance companies are prohibited from creating profiles in our communities. Please direct inquiries to support@patientslikeme.com.

2.) Open text from a member's private profile is provided verbatim in Table 1, data which they have not decided to share publicly or with the researchers. A search within PatientsLikeMe for this string, or fragments of it, would quickly identify this patient. This would appear to be in violation of typical standards of medical research ethics.

Furthermore our research section has a number of FAQs directed to researchers which would have made clear the correct procedure to be followed: <https://www.patientslikeme.com/research/faq>

Given the trust our patients put in us, we are responsible for ensuring that their data is protected from misuse, whether intentional or accidental. Please ensure that any screenshots, quotes, or data that is from the logged-in part of PatientsLikeMe is retracted/deleted from the publication and any copies on repositories available on the Internet as soon as possible. Furthermore please delete any data obtained from the logged-in portion of PatientsLikeMe from your servers as soon as possible.

Sincerely,

Paul Wicks

Paul Wicks, PhD.

VP of Innovation

patientslikeme

m: [+44 \(0\)7813 037 069](tel:+44207813037069)

pwicks@patientslikeme.com

www.patientslikeme.com | [Twitter](#) | [Facebook](#) | [Blog](#)