



# Risks and benefits of sharing patient information on social media: a digital dilemma

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Social media (SoMe) has witnessed remarkable growth and emerged as a dominant method of communication worldwide. Platforms such as Facebook, X (formerly Twitter), LinkedIn, Instagram, TikTok, and YouTube have become important tools of the digital native generation. In the field of medicine, particularly, cardiology, attitudes towards SoMe have shifted, and professionals increasingly utilize it to share scientific findings, network with experts, and enhance teaching and learning. Notably, SoMe is being leveraged for teaching purposes, including the sharing of challenging and intriguing cases. However, sharing patient data, including photos or images, online carries significant implications and risks, potentially compromising individual privacy both online and offline. Privacy and data protection are fundamental rights within European Union treaties, and the General Data Protection Regulation (GDPR) serves as the cornerstone of data protection legislation. The GDPR outlines crucial requirements, such as obtaining 'consent' and implementing 'anonymization', that must be met before sharing sensitive and patient-identifiable information. Additionally, it is vital to consider the patient's perspective and prioritize ethical and social considerations when addressing challenges associated with sharing patient information on SoMe platforms. Given the absence of a peer-review process and clear guidelines, we present an initial approach, a code of conduct, and recommendations for the ethical use of SoMe. In conclusion, this comprehensive review underscores the importance of a balanced approach that ensures patient privacy and upholds ethical standards while harnessing the immense potential of SoMe to advance cardiology practice and facilitate knowledge dissemination.

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## Graphical Abstract



## Keywords

Social media • Legal • Ethical • Privacy • Patient information • Education

## Introduction

Over the years, social media (SoMe) has evolved to become a major method of communication in society, with ~4.6 billion users worldwide.<sup>1</sup> Social media platforms are characterized by a web-based and/or smartphone mobile app with a unique interface, which facilitates the interactive creation and sharing of information through a virtual community. Facebook, X (formerly Twitter), LinkedIn, Instagram, TikTok, and YouTube are currently among the most popular platforms and have become an established form of communication for the current digital native generation. The individual platforms allow the sharing of different forms of information (text-based, image, or video-based) with variable flexibility for the type and amount of data to be shared.

The relevance of SoMe pertains not only to mainstream media but there is also a similar trend in its utilization in the field of medicine, especially in cardiology.<sup>2-4</sup> Prior generations of physicians were hesitant to use SoMe out of concerns about patient privacy, liability, lack of familiarity, and insufficient time to learn and use 'new-fangled' gadgets.<sup>4,5</sup> However, times have changed and SoMe, in particular, X (formerly Twitter), has become a forum of communication for professionals who use the platform to gain exposure to new research and to network with experts and colleagues around the world.<sup>6-8</sup> Most importantly, it is increasingly being leveraged for teaching and learning purposes in different forms, such as challenging or exciting patient case histories, X (formerly Twitter) Journal Clubs, Tweetorials, and (virtual) conferences. Additionally, SoMe has become important for both cardiovascular journals and medical professional organizations, such as the European Society of Cardiology (ESC), to disseminate cardiovascular health information, new scientific findings, challenging case material, and education globally.<sup>9,10</sup>

While SoMe offers obvious benefits, there are also challenges, pitfalls, and even risks associated with sharing patient information which are related to the ethical, legal, and social implications of its utilization. Whereas scientific journals use a peer-review process and have strict

guidelines on consent before publication, this is not the case for SoMe. Moreover, advice on the application, deployment, and professional etiquette of SoMe is limited.<sup>11</sup> It is for this reason that the *European Heart Journal—Digital Health* assembled a group of experts ranging from cardiologists in different stages of their career, scientists, lawyers, policy-makers, and patients to review the current applications, legislation, and perspectives regarding the sharing of patient information on SoMe. In this review, the authors offer advice on the use of SoMe within the professional field of cardiology and future routes along which both practitioners and patients might progress.

## Application of social media in education and science

Cardiovascular medicine has seen major technological advances in the last decade that have enabled us to transition from traditional methods of teaching to digital learning.<sup>12</sup> The COVID-19 pandemic and the subsequent disruption of daily life and traditional education catalysed the use of digital solutions and SoMe for rapid communications and dissemination of knowledge.<sup>13</sup> The virtual nature of SoMe allows for attendance by anyone, from anywhere and at any time provided there is access to the internet and a smart device.<sup>14</sup> In contrast to traditional case teaching, sharing clinical cases and images on SoMe provides rapid and dynamic feedback from a global community of peers. Discussion can be planned in specific communities or by the use of a specified hashtag and has the potential to reach a bigger, broader, and more diverse audience than a traditional meeting or lecture.<sup>15</sup> An example is the use of the hashtag #CardioX (formerly Twitter) which refers to a community of individuals interested in cardiovascular science. It has grown tremendously over time and has been used over 1 000 000 times since October 2017.<sup>16</sup> Another important instructional strategy is the use of a 'Tweetorial', which is a collection of short tweets about a given subject to teach others about a certain topic in medicine or cardiology.<sup>17,18</sup> Cardiologists have made this part of their





time of the processing and technological developments' (Recital 26 GDPR). In the context of sharing patient data on SoMe, once data are anonymized, the GDPR requirements do not apply anymore, as long as the patient cannot be identified or is identifiable. This means that such data can be freely shared if other legal obligations (such as confidentiality) are met. However, anonymization needs to be monitored as conditions may change, and new technology, along with extra data, could lead to the patient becoming identifiable.

## Consequences for publication and social media policy

Almost all scientific journals publish case reports, flashlights, and images that give narrative descriptions of individual patients or details of their investigations. It is generally accepted that the publication of case reports requires the patient's consent, and there is a relatively standard approach to this process. However, published case reports often attract SoMe interest and may therefore become the subject of reception and discussion amongst medical and lay audiences. Most journals do not specifically address this type of dissemination or require that consent should be obtained for this. It is clear that work needs to be done to lift the practices of facilitating the patients' autonomy in the context of print publishing into the contemporary setting of dissemination to a SoMe audience.

We propose that whilst the regulatory requirements on consent (in particular when read in conjunction with the most recent data protection legislation) provide a clear framework for good practices in relation to obtaining consent, the context of SoMe use may provide an opportunity to rethink this field, and to acknowledge that a different balancing of rights and interests is required. In addition, the patient's ability to accurately gauge the consequences of exposure to SoMe may be much more developed than in conventional contexts of case study publishing.

### Consent for the publication of case reports

Authors frequently assume that consent to undergo an investigation or for inclusion within a clinical study is sufficient consent for the publication of a case report. Other authors claim that advice from their local ethics committee or institutional review board is that consent is not required. However, the International Committee of Medical Journal Editors, Committee on Publications Ethics (COPE), and CAse REport (CARE) guidelines state that it is mandatory that specific consent is obtained for the publication of the details of an individual or small group of patients in a case report or case series.<sup>24–26</sup> From an ethics perspective, it is common that where the sphere of confidence in relation to a patient's private health information is expanded (without the objective being the patient's best interests), it is a requirement to obtain informed permission to do so (consent). Formally, consent should be a witnessed and dated statement from a patient after viewing and preferably reading the case report and having had an opportunity to ask and have answered questions about the report. A possible procedure on how to ask for consent for a case report is included in [Table 3](#). There is a controversy about whether the signed consent should be included with the manuscript when submitted for publication. For example, BMJ Case Reports insists that the consent form is sent to the journal, whilst most other journals do not. Receipt of the consent form may reassure the editor that consent has been obtained but also identifies the patient. The journal must arrange a mechanism whereby handling editors do not have the opportunity to review the consent and that any journal staff involved in any of the SoMe activities of the journal remain blinded to the identity of the patient. The consent form must be stored safely. COPE discourages journals from reviewing consent forms.<sup>24</sup> An alternative approach that should reassure the journal that consent has been obtained is the mandatory inclusion in the publication of a statement from the author that 'written consent has been obtained and stored with the medical records of the patient'. There are obvious but

**Table 3 Procedure to obtain consent to publish patient data as case report in a journal or on social media**

#### Obtaining consent for a case report

- Provide the patient with an oral and/or written explanation of the consent process and the reasons for seeking consent
- Reassure the patient that all identifying marks have been removed from the material and that the patient will remain anonymous so far as is possible
- Provide the patient with a copy of the case report so that it can be viewed and, if possible, read; questions from the patient should be encouraged and addressed
- Provide a written/typed/printed consent form (not merely oral consent); journals may provide a consent form template
- Include the title of the case report
- Obtain a dated signature from the patient (or legally responsible relative)
- Obtain a dated witness signature; the witness is usually the responsible physician or delegate
- File the consent form in the patient's medical record
- State in the manuscript that written consent has been obtained and that the consent form has been lodged in the patient's medical record

exceptional circumstances when consent cannot be obtained such as when a patient has died and has no relatives. However, it is not satisfactory to waive consent simply because the patient is 'lost to follow-up' unless the report is of substantial significance. In such a case, after agreement with the editor, the author should insert a statement in the publication that 'written consent has not been obtained because ...'.

### Consent for social media consequences of case report publication

Case report journals encourage SoMe reporting of material published in the journal since it will spread educational knowledge and add to its Altmetric score, an important indicator of the impact of the publication and the journal.<sup>27,28</sup> The journal usually appoints a team of SoMe editors to systematically promote material on SoMe. The author(s) of the case report is usually asked to participate. Author participation, however, introduces a 'wild' element regarding the anonymity of the subject of the case report since additional material relevant to the patient, not seen or edited by the journal and possibly not thoroughly checked regarding patient de-identification, may be introduced. This important concept should be mentioned in the 'instructions to authors', letters of acceptance, letters confirming publication, and any communication from the SoMe editorial team. It should also be covered in the reassurances made to the patient about SoMe exploitation.

Neither COPE nor CARE gives any consideration to consent for SoMe stemming from a case report but the BMJ Case Reports consent letter contains the following statement: 'The article, including the Material, may be the subject of a press release, and may be linked to from SoMe and/or used in other promotional activities'.<sup>24,26,29</sup> Other than stating that the article will be posted on the BMJ Case Reports website, no further explanation is given.<sup>29</sup> By example, European Heart Journal - Cardiovascular Reports does request consent for SoMe activity stemming from the report, but its sample consent form does not mention this.<sup>30</sup> A statement affirming that consent has been obtained should

**Table 4** General recommendations regarding use of social media

- **Before posting patient data make sure the post is compliant with GDPR. It is important to remember that anonymization is not enough to prevent the identification of the patient. As a result, stay away from contemporaneous posting and use caution when using uncommon presentations as they may be easily identifiable**

- Abide by institutional codes, if available, of conduct regarding the use of SoMe
- Procure written consent from patients to use their clinical information for educational purposes including SoMe
- Use respectful language when posting about a patient. If any emoticons are included these should also reflect respect towards the patient
- Maintain a professional attitude in your online presence; the reputation of the doctors, their institutions, and the larger medical community may be tarnished by aggressive or insulting discussions on SoMe. Moreover, they may also offend and confuse patients
- SoMe should be used as a discussion forum in adjunct to the relevant and available literature including societal practice guidelines
- Refrain from offering medical advice on SoMe
- Learn from discussions regarding areas of unfamiliarity but refrain from claiming any expertise in these fields
- Ensure the quality of the discussion and/or scientific evidence presented on SoMe
- Avoid any form of plagiarism

Recommendation regarding consent for the publication and associated SoMe activities

- **Journals that accept case reports, flashlights, or images should require written patient consent**

- A template consent form should be provided
- All identifying marks should be removed from patient reports and any illustrations
- Patient consent forms should be filed with the medical records of the patient
- A statement that written consent has been obtained from the patient and filed in the medical record of the patient should be contained within the printed manuscript
- If patient consent cannot be obtained the report should be declined or the failure to obtain consent should be justified, agreed with the editor and stated in the manuscript
- The patient consent form should include consent for SoMe triggered by the report and by the activity of the journal and the author(s)
- Presentation of case reports at meetings should require a similar consent process to that required for journal publications; patient identifiers should be removed from the presentation
- Patient-related SoMe activity by a responsible physician should require a similar consent process to that required for journal publications; patient identifiers should be removed from the activity
- Patient-related SoMe activity by a responsible physician in the absence of patient consent is not encouraged, but if undertaken for an important justified reason the patient's identity should be protected

Recommendations regarding essential elements on SoMe in the consent form

- Consent includes the possibility that the case report may stimulate global SoMe attention
- Case reports will be published online and, if in an open-access journal, will be freely available to all
- Case reports may be advertised by the journal on its website and information from the report may be disseminated on SoMe, such as X (formerly Twitter), by the journal editors/staff
- Physicians interested in the case may further disseminate the report or parts of the report and add to the discussion of the case; the physician must not introduce further data from which the patient may be identified
- The report may stimulate non-medical interest from, for example, newspaper journalists
- The author and the journal have done their best to retain the anonymity of the patient(s) and will continue to do so during SoMe discussions, but anonymity cannot be guaranteed

SoMe, social media; GDPR, General Data Protection Regulation.

be stated by the author(s) in the manuscript. The form should also alert the patient to probable interest from SoMe participants, particularly, other healthcare professionals and also, perhaps from journalists and others who take an interest in medical issues. The patient should be reassured that every effort has been made by the journal not to publish any material that could identify the patient, but that may not be completely protected. In this regard, it would be appropriate but difficult to afford patients significant levels of control in relation to the disposition of their personal data, in the form of a SoMe publication, over the internet. One approach would be to seek broad consent (between the healthcare professional and the patient) to prepare a SoMe publication. The author can provide the patient with a copy of the publication and an assessment of its potential reach.

### **Consent for social media activity not related to case report publication**

Physicians participating on SoMe may introduce information about their patients, whose cases have not been reported in the literature and for whom no previous consent has been obtained, in several ways. Firstly, many medical conferences have sessions where physicians present patient case reports to largely, but not exclusively, medical audiences. Aspects of these case reports frequently attract SoMe attention. Since these events are planned well in advance, there is ample opportunity for physicians to obtain consent for the presentation and for possible SoMe ramifications. The consent form and its content should be similar to the consent form used for case report publications.







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