

## Patients and their health records: one entity in two manifests

<sup>1-4</sup>Adeleke IT, <sup>5</sup>Suleiman-Abdul QB, <sup>6</sup>Ishaq IA

<sup>1</sup>Editor-in-Chief, International Journal of Health Records & Information Management;

<sup>2</sup>Department of Health Records, Federal Medical Centre, Bida, Nigeria; <sup>3</sup>Health Informatics Research Initiatives in Nigeria; <sup>4</sup>Centre for Health and Allied Researches, Bida, Nigeria; <sup>5</sup>School of Health Information Management, University of Ilorin Teaching Hospital, Ilorin, Nigeria; <sup>6</sup>Phlebotomy Unit, Federal Medical Centre, Bida, Nigeria.

Corresponding Author:

Adeleke IT., Editor-in-Chief, International Journal of Health Records & Information Management, Department of Health Records, Federal Medical Centre, Bida, Nigeria. Email:

[Ibratadeleke\\_aliseyin@yahoo.com](mailto:Ibratadeleke_aliseyin@yahoo.com)

### Abstract

**Background:** Patients' health records are essential for good healthcare provision. The quality depends on accurate and prompt documentation of the care provided. Regular analysis of records' contents is essential for improving quality of care. This paper look at patients input into the management of their health records.

**Methodology/Results:** Searches into literatures on patients' confidence into how their health records are documented and secured in the hospital are the paramount focus of this study. The outcomes revealed that patients level of awareness of how their health records are being used in researches are increasing. The patients' supports in this will be enhanced as they have access to their health records too, thereby affording them to play active roles in their care management. However, patients were concerned about reduced confidentiality with their records held on computer.

**Conclusion:** The researchers concluded that to respect patients' autonomy, privacy and consent choices, efforts should be geared toward health-services users' active roles in their care process. One way is to facilitate patients having gainful access to their records and a standard and documented way of obtaining consents from them to use the records in research. These will go a long way in evolving better health outcome and in effect, improved healthcare quality.

**Keywords:** Access; Confidentiality; Health Records; Privacy; Protected Health Information

---

### Introduction

The patient's health record is an important compilation of facts about his/her life and health. It includes documented data on past

and present illnesses and treatment written by health care professionals caring for the patient.<sup>1,2</sup> The health records are essential for good healthcare and their quality depends on

REVIEW Adeleke *et al.*: Two manifests of patients' health records accurate and prompt documentation of the care provided.<sup>3</sup> Though, the hospital generates and takes custody of the records, the patients are the reasons the health records are initiated.<sup>4-7</sup> Health records are the visible evidence of the clinical activities and the regular analysis of contents contributed to the hospital's accomplishments. Such achievements are a valuable resource for enabling patients' participation in their healthcare.<sup>8,9</sup> Since they are the basis of any health institution, documentation of every contact of each patient with a healthcare provider must be comprehensive and robust to the scrutiny of auditors or attorneys.<sup>8</sup> This review elucidates the relationship between the patients and their health records as two sides of a coin. The review, though not exhaustive, discusses the importance patients attached to their health records and how such should be handled.

### **Methodology/Results**

The review into patients' confidence on how their health records are documented and secured in the hospital was attained by searches of relevant literatures. The outcomes revealed that patients level of awareness of how their health records are being used in researches are increasing. The proper engagement of patients in this will earn their supports in facilitating documentation of enriching the illness

stories. This will be enhanced as patients started having access to their health records too, thereby affording them to play active roles in their care management. The findings and import will be discussed under successive headings.

### **Patients' health records management in the contemporary healthcare settings**

Lately, it has been argued that the management of health records should not solely be in the hands of competent professionals. This had been attributed some skilled handlers who do not understand their respective responsibilities toward good health records practice with gross inadequacies in the documentation processes.<sup>3,10-16</sup> The aforementioned challenges facing patients' health records have propelled several calls for computerization of health records and information management processes. Interestingly, studies have revealed that most healthcare settings especially from low and middle income countries like Nigeria are not computerized and that handlers of patients' health records lack the right computing skills to effectively handle computerized healthcare systems.<sup>17-23</sup> Nevertheless, there have been quests for training and retraining among health records professionals, an indication for good health records practice.<sup>24-</sup>

26

## REVIEW

Adeleke *et al.*: Two manifests of patients' health records

Patients always want satisfactory services and when they are involved in the management of their health records, they play active and collaborative role for a better care management.<sup>9,27</sup> Although some patients find reading their medical notes confusing or offensive, involving them directly in the management of their care has been described as a means of securing interactive and accountable technologies.<sup>28,29</sup> Patients nowadays are expected to interact with the information in their health records outside the health care facilities and even share their health information with others.<sup>30</sup>

### **When patients are granted access to their health records**

Patients have right to information contained in their health records but, gaining access to such records is often a challenge.<sup>28,35</sup> In spite of their level of education and involvement in their care, most patients found viewing their health records useful and understood most of the content, though they sought for explanations on some confusing medical terms and abbreviations.<sup>31</sup> This beckons on physicians and other care givers to take time to explain the language in use and to be more respectful in written notes.<sup>28</sup> Many of these patients believe that viewing their health records translates into care-related decisions and actions, and they wish they could add personal information to the records.<sup>31,32</sup>

Although many patients found medically insignificant errors in their records, the majority were satisfied that the health information contained in their health records was complete and accurate.<sup>33</sup> However, some patients are worried by the idea of seeing their own health records as they might not be able accommodate viewing their abnormal test results. Some other groups of patients are concerned about the security and confidentiality of their records.<sup>31,33</sup> Overall, patients' access to their health records will afford them to play active roles in their care management. Therefore, caregivers should work in partnership with patients to develop systems essential to their success.

### **When patients' health record is used in research**

Patients have confidence that their health records is not only secured in the hospital, but are also aware that their caregivers use their health records in research which they are supportive as such research should help improve the quality of health care.<sup>36,39,43,44</sup> However, some patients would frowned when their health records were used for research purposes without getting informed consent from them.<sup>36,41</sup> Despite their want of exclusive consent, their trust and knowledge about the use of their health records in research tend to make them recommend less-stringent process to obtain consent.<sup>36,39,41</sup>

Considering the public varying preferences, especially in obtaining individual's consent, this presents logistical challenges in using patients' health records in research.<sup>41</sup> Therefore, systems for obtaining permission when patients are admitted should be standardized.<sup>45</sup> Nevertheless, emerging regulations on human subjects permit much access to electronic medical records and residual clinical biospecimens without individual informed consent.<sup>43</sup> Resolution of uncertainties surrounding legislation on the use of information would be helpful to clinicians.<sup>45</sup>

#### **When patients' health record is held on computer or in the Cloud**

Keeping patients' health records on computers or other technologically-driven media have offered the patients invaluable advantages. For example, care card, which is an electronic replica of physical records, empowers patients by giving them access to their own health records. With care card, a patient can see the records, read it, and could choose to obtain the readers which give them access to it.<sup>44</sup> However, patients were concerned about reduced confidentiality with their records held on computer.<sup>45,46</sup> They expressed concerns about loss of confidentiality when doctors used these systems. Those with experience of computers were more aware of the limitations of

computers in terms of error, breakdown and potential loss of confidentiality but despite more knowledge of these problems, they still favoured use of computers in consultation.<sup>47</sup> Just that they want granular privacy control over sharing of information from therein.<sup>48</sup> Patients worry about the confidentiality of their computer record and it seems that those less familiar with computers, belonging to the female gender and those less aware of their GP's actions at the computer worry more.<sup>49</sup> Protecting patient confidentiality becomes the personal responsibility of every participating patient.<sup>50</sup> By placing the patient at the center of healthcare data exchange and empowering the patient to become the steward of their own data.<sup>50</sup> Many patients opined that electronic format could ease record access and eliminate the problem of griffonage (incomprehensible handwriting). For maximum usefulness to patients, personal health records (PHRs) data may need to be comprehensive.<sup>51</sup> PHR has the potential to create a more complete and balanced view of the patient because it is owned, controlled and managed by the patient.<sup>52</sup> Providing patient control of healthcare information exchange is appealing in PHRs as it solves many of the privacy and consent issues faced by organizations desiring to exchange data today.<sup>49</sup>

### **Implications for health records management and healthcare services**

Although records viewed by patients today are most likely to be in paper format, which provides limited opportunity for comprehension support, record access improves shared management, improved interactions with healthcare providers, improved health outcomes and quality patients' decision making for improved care quality.<sup>53</sup> This is crucial for both the integrity of healthcare and biomedical research. In addition, patients need to trust their physicians, other care providers and health institutions. They need not to unnecessarily become suspicious or offensive that activities of potential interest to them especially as it affects their health records are being conducted without their knowledge.<sup>54</sup> It is good to note that involving patients in their care process is a means of securing interactive and accountable technologies capable of improving their healthcare and influencing health outcomes.<sup>29</sup>

### **Conclusion**

Patients highly value confidentiality of their health records but they also recognize the high worth of health records research. It can be said that the patients and his health records are inseparably-linked elements. To respect patients' autonomy, privacy and consent choices therefore, efforts should be geared

toward their active roles in their care process, gainful access to their records and a standard and documented way of obtaining consents for use in research. These will go a long way in evolving better health outcome and in effect, improved healthcare quality.

### **References**

1. World Health Organization. Medical Records Manual Revised: A Guide for Developing Countries. WHO Library Cataloguing in Publication Data, 2006.
2. Huffman EK. Medical Record Management. 9th edn. Berwyn, Illinois: Physician's Records Company, 1990:596-7.
3. Adeleke IT, Adekanye AO, Onawola KA, et al. Data quality assessment in healthcare: a 365-day chart review of inpatients' health records at a Nigerian tertiary hospital. 2012; 19:1039-1042. doi: 10.1136/amiajnl-2012-000823.
4. Adeleke IT, Adekanye AO, Adebisi AA, James JA, Omokanye SA, Babalola A. Patients' health records in research: perceptions and preferences of Nigerian patients. IMAN Medical Journal. 2018;4(1):16-28.
5. Thomas J. Medical records and issues in negligence. Indian J. Urol. 2009;25(3):384-388.
6. Anonymous. Fast facts: who owns health information? Health Information and the Law. 2015. Available at: [www.HealthInfoLaw.org](http://www.HealthInfoLaw.org). (Accessed on 10/03/2018).
7. Asai A, Ohnishi M, Nishigaki E, et al. Attitudes of the Japanese public and doctors towards use of archived information and samples without informed consent: preliminary findings based on focus group interviews. BMC Medical Ethics 2002, 3:1.
8. Durking N. Using records review as a quality improvement process. Home Healthc Nurse 2006; 24:492-502.
9. Keselman A, Slaughter L, Arnott-Smith C, et al. Towards consumer-friendly PHRs: patients' experience with reviewing their

- health records. AMIA 2007 Symposium Proceedings: 399-403.
10. Adeleke IT, Suleiman-Abdul QB, Aliyu A, Ishaq IA, Adio RA. Deploying unqualified personnel in health records practice – role substitution or quackery? implications for health services delivery in Nigeria. *Health Inf Manag.* 2018; 20.
  11. Adeleke IT, Adekanye AO, Adefemi SA, et al. Knowledge, attitude and practice of confidentiality of patients' health records among healthcare professionals at Federal Medical Centre, Bida. *Niger J Med.* 2011;20(2):228-35.
  12. Shrier I, Green S, Solin J, *et al.* Knowledge of and attitude toward patient confidentiality within three family medicine teaching units. *Acad Med.* 1998; 73:710-12.
  13. Adeleke IT, Ezike SO, Ogundele OA, Ibraheem SO. Freedom of information act and concerns over medical confidentiality among healthcare providers in Nigeria. *IMAN Medical Journal.* 2015;1(1):21-28.
  14. Adeleke IT, Ajayi OO, Jimoh AB, Adebisi AA, Omokanye SA, Jegede MK. Current clinical coding practices and implementation of ICD-10 in Africa: a survey of Nigerian hospitals. 2015;3(1-1):38-46.
  15. Abdulkadir AY, Yunusa GH, Tabari AM, et al. Medical record system in Nigeria: observations from multicentre auditing of radiographic requests and patients' information documentation practices. *Journal of Medicine and Medical Science.* 2011;2(5):854-858.
  16. Adebisi AA, Adeleke IT, Abdulghaneey OO, Abdulsalam A. Assessment of quality of healthcare data management in antiretroviral records at Federal Medical Centre, Bida in North-central Nigeria. *International Journal of Health Records & Information Management.* 2018; 1(1):25-29.
  17. Adeleke IT, Lawal AH, Adio RA and Adebisi AA. Information technology skills and training needs of health information management professionals in Nigeria: a nationwide study. *Health Information Management Journal.* 2014; 44(1):1-9.
  18. Adeleke IT, Erinle SA, Ndana AM, Anaman TC, Ogundele OA, Aliyu D. Health information technology in Nigeria: stakeholders' perspectives of nationwide implementations and meaningful use of the emerging technology in the most populous black nation. *American Journal of Health Research.* 2015;3(1-1):17-24.
  19. Adeleke IT, Adekanye AO, Jibril AD, Danmallam FF, Inyinbor HE, Omokanye SA. Research knowledge and behaviour of health workers at Federal Medical Centre, Bida: a task before learned mentors. *El Med J.* 2014; 2(2): 105-109.
  20. Adeleke IT, Salami AA, Achinbee M, Anamah TC, Zakari IB, Wasagi MH. ICT knowledge, utilization and perception among healthcare providers at National Hospital Abuja, Nigeria. *American Journal of Health Research.* 3(1-1):47-53.
  21. Adeleke IT, Asiru MA, Oweghor BM, Jimoh AB, Ndana AM. Computer and internet use among tertiary healthcare providers and trainees in a Nigerian public hospital. *American Journal of Health Research.* 2015;3(1-1):1-10.
  22. Adeleke IT. Electronic migration, quackery denunciation and professional regulations: the roles of health records professionals in rebuilding confidence in the Nigerian healthcare system. *International Journal of Health Records & Information Management.* 2018;1(1):1-3.
  23. Omokanye SA, Adeleke IT, Achinbe M, Adeoti DI, Ogundiran LM, Wasagi MH. Opinions of healthcare professionals at Federal Medical Centre Bida on barriers to successful implementation of electronic health record (EHRs) in Nigeria. *International Journal of Health Records & Information Management.* 2018;1(1):30-35.
  24. Suleiman-Abdul QB, Adeleke IT, Ajayi EO, Sule IA, Omar-Amao F, Adeoye WA. Knowledge, attitude and perceptions of health information management students toward anatomy and physiology. *International Journal of Health Records & Information Management.* 2018;1(1):15-19.
  25. Ojo AI. Repositioning health information management practice in Nigeria: suggestions for Africa. *Health Inf Manag.* 2017; 1.
  26. Adeleke IT. Evolving a scholarly journal for health records in Nigeria: issues and prospect. *International Journal of Health Records & Information Management,* 2018;1(1):70.

27. Adekanye AO, Adefemi SA, Okuku AG, Onawola KA, Adeleke IT, James JA. Patients' satisfaction with the healthcare services at a North central Nigerian tertiary hospital. *Niger J Med.* 2013; 22(3): 218-224.
28. Patrick K. Patients and their medical records: It is time to embrace transparency. *CMAJ.* 2014; 186(11).
29. Georgiou A, Callen J. The role of health information management in health reform. *HIM J.* 2011;40(2):4-5.
30. Pratt W, Unruh K, Civan A, Skeels M. Personal Health Information Management. *COMMUNICATIONS OF THE ACM* January 2006/Vol. 49, No. 1. 51-55.
31. Canadian Medical Association. CMA Policy Summary. Confidentiality, ownership and transfer of Medical records. *CAN MED ASSOC J.* 1985; 133:142A.
32. Pyper C, Amery J, Watson M, Crook C. Patients' experiences when accessing their on-line electronic patient records in primary care. *British Journal of General Practice*, 2004, 54, 38-43.
33. Keselman A, Slaughter L, Arnott-Smith C, et al. Towards consumer-friendly PHRs: patients' experience with reviewing their health records. *AMIA 2007 Symposium Proceedings* Page – 399-403.
34. Hassol A, Walker JM, Kidder D, et al. Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. *J Am Med Inform Assoc.* 2004; 11:505–513. DOI 10.1197/jamia.M1593.
35. Bernadt M, Gunning L, Quenstedt M. Patients' access to their own psychiatric records. *BMJ* 1991; 303:967.
36. Adeleke IT, Adekanye AO, Adebisi AA, James JA, Omokanye SA, Babalola A. Patients' health records in research: perceptions and preferences of Nigerian patients. *IMAN Medical Journal.* 2018;4(1):16-28.
37. Willison DJ, Schwartz L, Abelson J, et al. Alternatives to Project-specific consent for access to personal information for health research: What Is the Opinion of the Canadian Public? *J Am Med Inform Assoc.* 2007; 14:706 –712. DOI 10.1197/jamia.M2457.
38. Botkin JR, Rothwell E, Anderson R, Stark LA, Mitchell J. Public attitudes regarding the use of electronic health information and residual clinical tissues for research. *J Community Genet* (2014) 5:205–213. DOI 10.1007/s12687-013-0175-8.
39. Willison DJ, Steeves V, Charles C, et al. Consent for use of personal information for health research: Do people with potentially stigmatizing health conditions and the general public differ in their opinions? *BMC Medical Ethics* 2009, 10:10.
40. Willison DJ, Keshavjee K, Nair K, Goldsmith C, Holbrook AM. Patient consent preferences for research uses of information in electronic medical records: interview and survey data. *BMJ.* 2003; 326:373.
41. Damschrodera LJ, Prittsc JL, Neblod MA, Kalarickalb RJ, Creswelle JW, Haywarda RA. Patients, privacy and trust: Patients' willingness to allow researchers to access their medical records. *Social Science & Medicine* 64 (2007) 223–235.
42. Riordan F, Papoutsis C, Reed JE, Marston C, Bell D, Majeed A. Patient and public attitudes towards informed consent models and levels of awareness of Electronic Health Records in the UK. *Int J Med Inform.* 2015 Apr; 84(4): 237–247.
43. Campbell B, Thomson H, Slater J, Coward C, Wyatt K, Sweeney K. Extracting information from hospital records: what patients think about consent. *Qual Saf Health Care* 2007; 16:404–408. doi: 10.1136/qshc.2006.020313.
44. Grey DP, Hall MS. A new approach to medical records. *West of England Medical Journal* Volume 105(i) March 1990.
45. Pringle M, Robins S, Brown G. Computers in the surgery: the patient's view. *BMJ* 1984; 288: 289-291.
46. Rethans JJ, Hoppener P, Wolfs G, Diederiks J. Do personal computers make doctors less personal? *BMJ* 1988; 296: 1446-1448.
47. Ridsdale L, Hudd S. Computers in the consultation: the patient's view. *British Journal of General Practice*, 1994, 44, 367-369.
48. Caine K, Hanania R. Patients want granular privacy control over health information in electronic medical records. *J Am Med Inform Assoc* 2013; 20:7–15. doi:10.1136/amiajnl-2012-001023.
49. Garcia-Sanchez R. The patient's perspective of computerized records: a questionnaire survey in primary care.

## REVIEW

### Adeleke *et al.*: Two manifests of patients' health records

- Informatics in Primary Care 2008; 16:93–9.
50. Halamka JD, Mandl KD, Tang PC. Early experiences with Personal Health Records. *J Am Med Inform Assoc.* 2008; 15:1–7. DOI 10.1197/jamia.M2562.
  51. Keselman A, Slaughter L, Arnott-Smith C, et al. Towards consumer-friendly PHRs: patients' experience with reviewing their health records. *AMIA 2007 Symposium Proceedings* Page – 399-403.
  52. Ball MJ, Smith C, Bakalar RS. Personal Health Records: Empowering Consumers. *Journal of Healthcare Information Management.* 2006;21(1):76-86.
  53. Fisher B, Bhavnani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. *J R Soc Med* 2009; 102: 538–544. doi:10.1258/jrsm.2009.090328.
  54. Kass NE, Natowicz MR, Hull SC, et al. The Use of Medical Records in Research: What Do Patients Want? *J Law Med Ethics.* 2003; 31(3): 429–433.

Conflict of interest: Nil