



# HHS Public Access

Author manuscript

*Med Care*. Author manuscript; available in PMC 2019 February 01.

Published in final edited form as:

*Med Care*. 2018 February ; 56(2): 107–110. doi:10.1097/MLR.0000000000000857.

## Commentary: Copyright Restrictions versus Open Access to Survey Instruments

**Ron D. Hays, PhD,**

Division of General Internal Medicine and Health Services Research, Center for Health Improvement for Minority Elderly, David Geffen School of Medicine at UCLA, 911 Broxton Avenue, Los Angeles, CA 90095

**Robert Weech-Maldonado, PhD, MBA,**

Department of Health Services Administration, Deep South Resource Center for Minority Aging Research, University of Alabama at Birmingham, 1720 2nd Avenue South Birmingham, AL 35294-0113, (205) 996-5838; (205) 975-6608

**Jeanne A. Teresi, EdD, PhD,**

Columbia University Stroud Center at New York State Psychiatric Institute, 1051 Riverside Drive, Box 42, Room 2714, New York, NY 10032; Research Division, Hebrew Home at Riverdale, 5901 Palisade Avenue, Bronx, NY 10471, 718-581-1132; 718-543-2477

**Steven P. Wallace, PhD,** and

Department of Community Health Sciences, UCLA Fielding School of Public Health, Center for Health Improvement for Minority Elderly, 10960 Wilshire Blvd., Ste 1550, Los Angeles, CA 90024, (310) 794-0910; (310) 794-2686 FAX

**Anita L. Stewart, PhD**

Institute for Health & Aging, Center for Aging in Diverse Communities, University of California San, 3333 California Street, Rm 350E, San Francisco, CA 94118, (415) 502-5207

---

A graduate student was threatened with a lawsuit and retraction of a published paper unless she paid thousands of dollars and signed a retroactive license for having used a measure without paying the fee. A doctoral student who complied with all the survey licensing requirements was not allowed to share her instrument with her dissertation committee nor provide examples of survey items in her dissertation. An investigator asked a measure developer for permission to use a measure; after not receiving a reply, she published an article which was later retracted by the journal when representatives of the measure developer complained that explicit permission had not been obtained (1). These and other similar cases (2) motivated us to write this commentary.

Although there are good reasons for imposing restrictions on use of published survey measures (3), there is not a consensus on what is reasonable versus excessive. But aggressive pursuit of “infringers” can hinder the advancement of knowledge. In this commentary, we advocate fewer restrictions on the use of published self-report measures for scientific

---

Corresponding author and reprints: Ron D. Hays, PhD, 310-794-2294; 310-794-0732 FAX, drhays@ucla.edu.

The authors have no conflicts of interest associated with this manuscript.

research. We summarize issues of copyright, permission and restrictions, fees for use, transparency and the consequences of non-compliance with restrictions. Recommendations to address raised concerns are made for developers, researchers (users), publishers, and funders.

Copyright protects the commercial interests of the holder while balancing a public interest in knowledge (4). Copyright “exists automatically when a literary or artistic work is fixed in some tangible medium of expression (4),” whether the author desires it or not (5). Waiving copyright protection requires an active process of authors notifying users that they abandon copyright and place the work in the public domain (6). Copyright protection thus applies regardless of whether (or not) a copyright notice appears on the survey measure or is registered with the copyright office (7). The copyright owner has exclusive rights and can authorize others to: 1) reproduce the copyrighted work; 2) create derivative works based upon the copyrighted work; 3) distribute copies of the copyrighted work to the public by sale or other transfer of ownership, or by rental, lease, or lending; and 4) display the copyrighted work publicly. The copyright holder can choose to authorize others to use their work without or with cost to others.

### **Permission needed to use instruments can vary from none to costly**

In our experience, many authors allow for non-commercial use of their tools by researchers without requiring written permission, a license, or a fee. For example, surveys developed at the RAND Corporation are freely available and no permissions are needed: “All of the surveys from RAND Health are public documents, available without charge. Please provide “an appropriate citation when using these products. .... There are no further permissions necessary (8).”

Some authors request or require that you obtain explicit approval to use their measures even if there is no cost. This can be motivated by a desire to keep track of how widely a scale is being used and to make sure the user has the most recent version and understands the correct way to apply the tool. For example, the Kidney Disease Quality of Life (KDQOL™) surveys are provided without charge to those who register at: [http://gim.med.ucla.edu/kdqol/kdqol\\_register.php](http://gim.med.ucla.edu/kdqol/kdqol_register.php).

Other instrument developers use the copyright status to put limitations on modifications and translations. For example, one site notes: “All of our questionnaires are copyrighted. They may not be altered, sold, translated into another language or adapted for another medium (e.g., computer, internet) without ..... permission. Warning: Some versions of our questionnaires found on other web sites may be unauthorised and may contain serious errors and must not be used (9).”

Similarly, HealthMeasures, which provides oversight for the National Institutes of Health (NIH) Toolbox, Patient Reported Outcomes Measurement Information System (PROMIS), Neuro-Quality-of-Life (Neuro-QoL), and Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me) states that the “user agrees not to adapt, alter, amend, abridge, modify, condense, make derivative works, or translate HealthMeasures instruments

without prior written permission from the (Department of Medical Social Sciences). In cases where permission is granted, User will be expected to evaluate the impact of approved modifications (10).”

Some authors charge fees for using published instruments; fees can include a licensing fee, administration fee, and/or fee for obtaining scoring algorithms. For example, use of the Patient Activation Measure® (PAM®), developed with funding by the Robert Wood Johnson Foundation, requires a licensing fee (11). As a result, researchers are looking for other alternatives such as the Altarium Consumer Engagement (ACE) Measure™ (12).

In cases where a measure was developed and tested without NIH funding, the fees can help defray some of the development costs. However, per respondent charges for using a single scale can make the cost of research expensive very quickly, especially if several such scales are used in a study. In these cases, potential users must decide if the charges are worth it.

### **Transparency versus confusion about when permission is needed**

The status of restrictions on a survey measure may change over time, making it confusing for researchers to know what they currently are. For example, some measures were initially available at no cost, but charges and other restrictions on use were imposed later. For instance, the Mini Mental State Examination (MMSE) was published in 1975 (13). The actual questions (although they were not standardized) were included in an appendix with no claim to copyright, providing implicit permission to use it. Note that at the time of publication, US copyright law required that a copyright notice be included to claim coverage; the standard changed to passive coverage with the US entry into the Berne Convention in 1988 (6).

However, in June 2000, the MMSE owners transferred copyright to a company, MiniMental, LLC, and that company transferred exclusive publication rights to Psychological Assessment Resources (PAR), Inc. in March 2001. PAR implemented strict restrictions on use of the MMSE including requesting existing users to retroactively remove brief wording of the items on websites and in published documents such as dissertations and theses. There is a fee of about \$1.48 for each administration of the MMSE (paid to PAR) (14). The transfer to PAR is referred to as a stealth transfer because it occurred after an instrument was in use for a long period of time. In fact, it had become the most widely used cognitive screening measure (with over 2 million unique references in the literature), including being part of electronic medical records such as in Kaiser Permanente and the Veteran’s Health Administration systems (15). In a perspective in the *New England Journal of Medicine* in 2011 about the MMSE, Newman and Feldman summarized its widespread clinical (bedside) use because of its simplicity and ubiquity (14) and asked what researchers could do “to ensure that our colleagues can use the tools we develop to improve patient care?” (p. 2448). Newman elaborated on this in 2015, lamenting on the demise of a ubiquitous bedside tool (16). In response to these restrictions, Tsoi and colleagues summarized alternatives to the MMSE (17), enabling the scientific advancement of measurement of cognitive functioning. Although the MMSE is slowly being replaced by other screening measures, many researchers have lost the ability to compare newer data with those from earlier studies, and a

generation of clinicians for whom the MMSE was a familiar, memorized benchmark, have had to modify their assessment routines.

## Variation in consequences

The consequence of not obtaining appropriate permission to use a measure can vary. For example, some journals will not publish a paper if the authors do not provide proof that they have permission to use the measures in their study. The naïve user of a copyrighted measure may also be subject to financial penalties. Discussions of fair use practices suggest that: “If someone has good reason to believe that a use is fair — but later finds herself on the wrong end of a court order — she is likely to be considered an innocent infringer at worst. Innocent infringers often don’t have to pay any damages to the copyright owner, but do have to cease the infringing activity and sometimes must pay the owner for the reasonable commercial value of that use (18).”

Nonetheless, innocent infringers have been the target of threatened lawsuits and faced demands of large sums of money for retroactive permission. For example, those using the Morisky Medication Adherence Scale (MMAS) without permission (“infringers”) have been aggressively pursued, despite the original four item scale being published in *Medical Care* in 1986 (19) and most of the information about the eight item scale appearing in a research journal in 2008 (20) that acknowledged NIH support. Infringers of the MMAS copyright have recently been pursued for very large payments and, in some cases, had to retract published articles, as documented by the Centers for Disease Control and Prevention (1). The current MMAS website which was established in 2016 (<https://www.whois.com/whois/morisky.org>) states clear restrictions on use but provides no information on licensing fees: “Permission for use is required. A license agreement is available from MMAS Research LLC.” The aggressive pursuit of those without licenses or permission appears to serve financial interests, and can hinder the advancement of knowledge. Because science involves incremental advances that build on past studies, the ability to use and modify existing measures is essential. For example, health disparities research often requires modifications of existing measures to ensure cross-cultural comparability across for different racial/ethnic and language subgroups of the population.

## Recommendations for developers of measures

For those developing measures and wishing to be clear about the conditions of use, we suggest using the Creative Commons (<https://creativecommons.org/>) to document requirements of use with widely acknowledged language and links to the site of the survey instrument itself. “Creative Commons helps you legally share your knowledge and creativity to build a more equitable, accessible, and innovative world.... Creative Commons provides free, easy-to-use copyright licenses to make a simple and standardized way to give the public permission to share and use your creative work—on conditions of your choice.” This is ideally done from the start but can be done any time after the measure is developed and published. Newman and Feldman describe this as “the principle of ‘copyleft’ from the open-source technology movement to encourage innovation and access while protecting authors’ rights.” (p. 2448) (14).

## Recommendations for researchers and users

Researchers and other users of survey instruments wishing to use an existing measure need to be vigilant and check the complete history of item development and evaluation. The onus is on the user to determine if explicit permission or fees are required for use. They also need to obtain permission and know the conditions of use. Locating the copyright holder may not be possible (e.g., contact information has changed or the original developer is deceased). If a researcher is unsuccessful in reaching the copyright holder, using the measure is at the user's own risk unless there is clear evidence that it is in the public domain (e.g. has an appropriate creative commons license listed). It is also possible that a search leads one to a "rogue" website that includes the instrument and scoring guide with no indication that permission or registration is required. Thus, the search process needs to be extremely thorough to ensure that any restrictions on use of the measure are identified.

We suggest researchers use freely available instruments and only pay for use of a measure if the cost is worth it to them (e.g., alternative measures have deficiencies). To the extent that the fees are constraining, it is worthwhile to look for measures that do not require payment, assuming equivalent measurement properties of the substitutes. Exploring alternatives can potentially result in finding a measure that is more contemporary or has been designed to be appropriate for a variety of population subgroups. As one on-line survey platform "PsychData" notes, "In some cases a researcher will initially identify one measure for their project only to find that the copyright holder is unwilling to permit use in an online survey or that they will only permit use via their proprietary online system .... In our experience, these researchers have always been able to quickly identify an equivalent or better alternative that was free or less restrictive (21)."

One virtuous outcome of researchers shifting to free measures is that declining demand for a costly measure will decrease its market value and reduce the attractiveness of charging for measures in the future. Such efforts are emerging; for example, legal departments within some universities are sending warnings to faculty about the use of restricted measures. A collective effort could help discourage developers from imposing undo restrictions and charging for use of their measures.

Similarly, measure developers who refuse to allow the modifications that are needed to be appropriate for health disparities populations or emerging data collection modalities should be informed that their measures are not being used because of those restrictions. Most measures have not been developed or evaluated using samples that include health disparities groups, so a blanket refusal to allow for modifications means that they are often inappropriate for use with those groups (22). Copyright holders that block modifications run the risk of impeding progress in understanding the health issues of disparities populations, possibly rendering their measures less relevant.

## Recommendations for funders

The National Institutes of Health (NIH) has a public access policy for peer-reviewed journal articles based on NIH-funded projects. All publications that result from NIH-funded

research are now required to submit an electronic version of their final, peer-reviewed manuscripts upon acceptance for publication to the National Library of Medicine's PubMed Central to be made publicly available no later than 12 months after the official date of publication (<https://publicaccess.nih.gov/policy.htm>). Some other funders, such as the Howard Hughes Medical Institute (HHMI), have similar requirements, noting that they have "long viewed the sharing of research materials and tools as a fundamental responsibility of scientific authorship (23)."

Additionally, data sharing is now required for many research efforts (24). For example, NIH proposals with over \$500,000 in direct costs in any year are required to include information about how the data they collect will be made publically available for others to use. There are also a growing number of data repositories such as Harvard Dataverse (<https://dataverse.harvard.edu/>).

However, these public access policies do not explicitly apply to measures. We suggest that a similar policy be adopted by NIH for instruments developed with NIH funds; thus, a measure developed primarily or entirely with NIH funding should be made available to the research community without charge. Such a policy could even include a requirement to post the instrument to a publicly-available website. To be effective more broadly, we would encourage other funders of measures/instruments, such as the Agency for Healthcare Research and Quality and Robert Wood Johnson Foundation adopt a similar policy.

## Recommendations for publishers

Free access to measures is desirable because this is most likely to advance scientific knowledge. *Medical Care* includes a clause in the instructions to authors that is consistent with this approach: "For articles describing development, validation, or testing of new measurement instruments (for example, health related quality of life, patient satisfaction, case mix adjustment), the instruments, including items and scoring instructions, must be available for research purposes to investigators requesting them." (<http://edmgr.ovid.com/mdc/accounts/ifauth.htm>)

## Conclusions

Psychometrically sound self-reported measures are cornerstones of research and clinical assessment. Measurement development is a resource demanding task and is often externally funded. It is thus imperative that such investments are not squandered through unnecessary restrictions that serve narrow interests. Just as data sharing has become mandated in many settings, it is also now time to advance measurement sharing as a means to ensure the best use of scarce resources.

## Acknowledgments

This commentary was supported in part through the National Institute on Aging's Resource Centers on Minority Aging Research (RCMAR) (P30-AG021684, P30-AG031054, and P30-AG15272). It was also supported in part by grants P30-AG028741, U54NS081765, R13AG023033 and HSOD-R01 HD079439. The commentary resulted from discussions over several years among these and other members of the RCMAR Measurement and Analysis Cores including Thomas N. Templin, Dan M. Mungas, Arie Kapteyn, and Steve M. Schwartz.

## References

1. Centers for Disease Control and Prevention. If you use this research tool without permission, you'll hear about it. Available at: <http://retractionwatch.com/2017/01/26/use-research-tool-without-permission-youll-hear/>, Accessed October 25, 2017
2. Marcus A. Pay up or retract? Drug survey spurs conflict. *Science*. 2017; 357:1085–1086. [PubMed: 28912224]
3. Revicki DA, Schwartz CE. Intellectual property rights and good research practice. *Qual Life Res*. 2009; 18:1279–1280. [PubMed: 19885743]
4. Leval PN. Campbell as fair use blueprint. *Wash L Rev*. 2015; 90:597–614.
5. Evans TM. “Safe harbor” for the innocent infringer in the digital age. *Willamette L Rev*. 2013; 50:1–42.
6. Turetzsky MW. Appying copyright abandonment in the digital age. *Duke L & Tech Rev*. 2010; 19:1–14.
7. CENDI Secretariat. Frequently asked questions about copyright: Issues affecting the US government. Oct 8. 2008 CENDI/2008-1 Available at: <https://www.cendi.gov/publications/04-8copyright.html#211>, Accessed October 26, 2017
8. RAND Health. Surveys. Available at: [https://www.rand.org/health/surveys\\_tools.html](https://www.rand.org/health/surveys_tools.html), Accessed October 26, 2017
9. Qoltech. Measurement of health-related quality of life & asthma. Available at: <http://www.qoltech.co.uk/>, Accessed October 26, 2017
10. Northwestern University. HealthMeasures Terms of Use. 2017. Available at: [http://www.healthmeasures.net/images/ASQMe/Terms\\_of\\_Use\\_HM\\_approved\\_1-12-17\\_-\\_Updated\\_Copyright\\_Notices.pdf](http://www.healthmeasures.net/images/ASQMe/Terms_of_Use_HM_approved_1-12-17_-_Updated_Copyright_Notices.pdf) Accessed October 26, 2017
11. Insignia Health. Patient Activation Measure. 2016. Available at: <http://www.insigniahealth.com/products/pam-survey>, Accessed November 1, 2017
12. Duke CC, Lynch WD, Smith B, et al. Validity of a new patient engagement measure: The Altarm Consumer Engagement (ACE) Measure™. *Patient*. 2015; 8:559–568. [PubMed: 26097010]
13. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975; 12:189–198. [PubMed: 1202204]
14. Newman JC, Feldman R. Copyright and open access at the bedside. *N Engl J Med*. 2011; 365:2447–2449. [PubMed: 22204721]
15. Fiore, K. Copyright issues hinder MMSE use: Neurologists forced to look for alternative cognitive screening tests. *MedPage Today*. 2015. Available at: <https://www.medpagetoday.com/neurology/dementia/52040>, Accessed October 25, 2017
16. Newman JC. Copyright and bedside cognitive testing: Why we need alternatives to the Mini-Mental State Examination. *JAMA Intern Med*. 2015; 175:1459–1460. [PubMed: 26053392]
17. Tsoi KK, Chan JY, Hirai HW, et al. Cognitive tests to detect dementia: A systematic review and meta-analysis. *JAMA Intern Med*. 2015; 175:1450–1458. [PubMed: 26052687]
18. Stanford University Libraries. Copyright registration and enforcement: how to get maximum protection from federal copyright laws. 2019. Available at: <http://fairuse.stanford.edu/overview/faqs/registration-and-enforcement/> Accessed October 25, 2017
19. Morisky DE, Green LW, Levine DM. Concurrent and predictive validity of a self-reported measure of medication adherence. *Med Care*. 1986; 24:67–74. [PubMed: 3945130]
20. Morisky DE, Ang A, Krousel-Wood M, et al. Predictive validity of a medication adherence measure in an outpatient setting. *J Clin Hypertens (Greenwich)*. 2008; 10:348–354. [PubMed: 18453793]
21. Psychdata. Library: Using copyrighted research materials with PsychData. 2001–2017. Available at: <https://www.psychdata.com/content/copyrighted-materials.asp>, Accessed October 26, 2017
22. Stewart AL, Thrasher AD, Goldberg J, et al. A framework for understanding modifications to measures for diverse populations. *J Aging Health*. 2012; 24:992–1017. [PubMed: 22495768]

23. Howard Hughes Medical Institute. Journal publishing policies. Available at: <https://www.hhmi.org/about/policies/open-access>, Accessed October 26, 2017
24. Teresi JA. Data sharing in the new real-world. *Med Care*. 2016; 54:1035–1037. [PubMed: 27846129]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript