



## FEATURE

## PATIENT COMMENTARY

# Open access: remember the patients

New information can save patients' lives. The ultimate stakeholders must have free, timely access to medical research, writes **Dave deBronkart**

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"Remember the ladies," wrote the future US first lady Abigail Adams in 1776 during the revolution, in a famous letter to her husband, the future president John Adams. "In the new code of laws which I suppose it will be necessary for you to make, I desire you would remember the ladies and be more generous and favorable to them than your ancestors."

It didn't happen quickly, nor easily: neither the Declaration of Independence, nor the US Constitution 13 years later, even mentions women, and achieving justice took 150 years. But on 4 June 1919 (just 100 years ago), Abigail's dream was expressed in part when Congress passed the 19th amendment, granting women the vote. A year earlier British suffragists had won partial equality with the Representation of the People Act 1918, which was improved in 1928 to give women fully equal voting rights.

## Remember the patients

A growing number of us patients are experiencing a comparable frustration at having newly minted knowledge kept from us—for financial reasons. While I fully understand the economic needs of the people who create and publish knowledge, I implore all of them—all of you—to "remember the patients." In your deliberations about policy, please remember the needs of the people for whose ultimate benefit your work exists. And modify the financial structure of this work, to prioritise not just creating the knowledge but also delivering it to those in medical need.

Families coping with desperate illness hope that everyone in the healing professions will do everything in their power to bring the newest findings to the point of need. Little do they know that those parties sometimes have other priorities. You should see the look of fear, even outrage, when they learn of this.

If I'm suffering, and remedies are developed, what needs should outweigh mine and keep those remedies hidden? If my baby has a potentially fatal disease, and useful knowledge has been developed, what needs should outweigh ours? Or, if my baby's condition is not fatal but potentially disabling, and new

knowledge has come to light, what needs should outweigh ours to keep that hidden?

Yet Brenda Denzler, a colleague of mine at the Society for Participatory Medicine who writes about her experiences of breast cancer,<sup>1,2</sup> benefited during her case because she had access to a paper her clinicians hadn't seen, which opened new choices in decision making. She had access solely because she worked in a university. Is this a sane basis for health policy: just-in-time application of new knowledge, through lucky coincidence?

## Research funding should include publication

When we fund research, the scope of that work is set to extend only to the creation of the new knowledge, not to its dissemination. This is the cause of all of the heartbreak, lost lives, and other scientific shortfalls (including new forms of bias) that can arise from making publication a separate budget item.

What if we were to rethink it from the perspective of sick people and decide that the work of knowledge creation isn't finished until it's been disseminated to all of them? If my sister dies because new knowledge was successfully developed but wasn't present at the point of need, whose failure is it? Whose finances were successfully protected, at the cost of her life?

I'll close with a humble update of the first two paragraphs of Ms Adams's famous letter:

*In the new code of regulations which I suppose it will be necessary for you to make, I desire you would remember the patients and be more generous and favorable to them than your ancestors.*

*Do not put such unlimited power into the hands of academics. Remember, all of them would be knowledge monopolists if they could. If particular care and attention is not paid to the needs of the sick people, we are determined to foment a rebellion, and will not hold ourselves bound by any laws in which we have no voice or representation.*

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- 1 Updates C. Research & Education. Brenda Denzler. <https://www.curetoday.com/community/brenda-denzler>.
- 2 Twitter. Brenda Denzler: @TheOrigBigScary. <https://twitter.com/theorigbigscary>.

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