

An inauspicious start for the US National Biospecimen Network

The UK is in the process of creating one. So are Iceland and Japan. Now, the US is planning to develop its own national biospecimen resource, specifically for cancer tissues. But the path to establishing this tissue bank is not proving straightforward, and the early stages of the effort have been greeted with some negativity in parts of the cancer research community.

An estimated 300 million tissue specimens representing more than 150 million medical cases are currently stored in repositories across the US, with over 20 million new specimens added each year. The disparate organizations that have banked these tissues for the past 30 years — hospitals, private companies, government labs — have done so in a way that suits their own use. Thus, the tissues have been amassed according to different technical methods of collection and storage, with varied levels of clinical annotation and informed consent.

This issue was articulated in March 2002 at a meeting of a non-profit group formerly called the National Dialogue on Cancer, now named C-Change, and the plan to develop a standardized system was born. Andrew von Eschenbach, director of the National Cancer Institute (NCI), helped to launch C-Change and remains the vice chair of its steering committee.

C-Change, in collaboration with the NCI, set up a subcommittee to gather intelligence on current banking systems and draw up a blueprint for a National Biospecimen Network (NBN). This document was formulated based on site visits and on the results of an NCI-sponsored questionnaire distributed at the American Association for Cancer Research meeting in July 2003, as well as on a specially commissioned report from the RAND Corporation.

In a press release posted on the C-Change website last July, von Eschenbach endorsed the value of an NBN, and two months later the blueprint

document was posted on that site for public comment. That comment period closed on January 31, 2004.

However, despite the scale of the initiative proposed, it appears that comparatively few investigators are familiar with the NBN plan. For example, Michael Pins of Northwestern University told the JCI that “this initiative was in large part done without significant input from the Cooperative Groups tissue banks,” although members of these groups were consulted.

Even some of those working in the field are confused over the details at the present time. Breast cancer researcher Lynne Dressler of the Lineberger Comprehensive Cancer Center, who recently completed a doctoral dissertation on human specimen use in genetic research, echoes the views of many who find the NBN development and structure somewhat unclear and the blueprint sketchy when it comes to defining the parameters of tissue collection.

Take the issues of sample demand and cost. One senior investigator, who wished to remain anonymous, told the JCI, “If you ask investigators whether they need more tissue, they’ll always say yes. But if you ask them how much they’re prepared to pay, then you find out they don’t need so many samples. My concern is that the real demand will be far below that currently imagined and that this will be a large and costly infrastructure that will provide expensive specimens. Some samples could be subject to Affymetrix-style evaluation and annotation. If so, this could make the specimen cost up to \$1,200.” The NCI’s Julie Schneider admits that the blueprint does not specify a price for tissues but presents a range of potential costs from \$70 to \$2,000, depending on the level of annotation.

Additionally, the blueprint document suggests that a three-year demonstration project should be set up as a precursor for the NBN. While it proposes that the project should set examples with five different types of tumors, it does not specify which cancers should be chosen. Although such issues were intended for discussion during the public comment period,

some researchers feel dismayed that a document that has taken 18 months to prepare and purports to have canvassed opinion from all parties with expertise and interest in tissue banking does not offer more precise information.

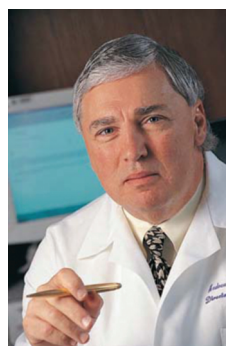
Underlying the unrest emanating from some sectors of the cancer community may be the fear that existing NCI resources will lose funding in favor of new NBN facilities. The blueprint outlines the cost of each type of service:

“Providing 25,000 samples at \$200 each would have an annual cost of roughly \$50 million (exclusive of start-up costs) . . . [whereas] approximately \$40 million per year is allocated currently by NIH to extramural programs for tissue banks.” It is questionable whether the two systems can coexist over the long term.

Another source of confusion is the level of involvement of the NCI in the NBN, an aspect examined repeatedly in issues of *The Cancer Letter*. This Washington newsletter charges that the C-Change group is acting in an advisory capacity to the NCI and should therefore adhere to the Federal Advisory Committee Act, which, at present, it does not.

A copy of the blueprint can be obtained via the C-Change website at <http://www.ndoc.org/>.

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Andrew von Eschenbach supports a new national tissue resource.