OTA Review of the Medical Follow-Up Agency

SUMMARY

The Medical Follow-Up Agency (MFUA), a division of the Institute of Medicine. specializes in biomedical and epidemiologic studies that rely on records of the Departments of Defense and Veterans Affairs. The agency' has operated continuously since it was created at the end of the Second World War. MFUA researchers conduct some research entirely within the agency, but for the most part, they collaborate with biomedical researchers from government (in particular the National Institutes of Health and the Departments of Defense (DoD) and Veterans Affairs (VA)) and universities. Several large studies currently under way by MFUA staff were mandated by law.

OTA was asked by the Chairmen of the House and Senate Committees on Veterans' Affairs to convene a workshop (similar to one held by OTA in 1988 also at the request of these committees) to address three main questions regarding MFUA:

1. What progress has been made in addressing the findings and recommendations made in OTA's 1988 review?

2. What level (if any) of core finding is required to keep MFUA operational?

3. How can the MFUA database be made more useful, including efforts to analyze data and disseminate research results?

The workshop was held on August 2, 1994, attended by MFUA staff (including the Director). other IOM officials (including the IOM president). officials and researchers from the Departments of Defense and Veterans Affairs, researchers from the National Institutes of Health. university-based researchers. and one member of a veterans' service organization (see Appendix 2).

This Background Paper summarizes OTA's findings with regard to the three questions asked. based on the workshop discussion as well as background information and discussions with various individuals before and after the workshop. A complete transcript of the workshop proceedings is also available.

Two things set MFUA apart among research agencies: first is its collective expertise m finding and interpreting military and veteran records and second, its medical records on more than 100,000 subjects belonging to about 700 defined groups of veterans ("cohorts" or "rosters"), These study cohorts allow for long-term follow-up studies on a wide range of medical topics which otherwise would be difficult at best, and in many cases impossible to do in the United States, While service personnel and veterans are the populations studied by MFUA. the findings of most of the studies are of general medical importance and apply to the population at large. not just veterans or the military'.

In 1988, when OTA was first asked to examine the issue of core finding, MFUA was at a transition point. It was without a permanent director and had experienced a relatively large staff turnover (especially for such a small **agency), its research agenda** appeared to be dwindling, and it had just been made part of the Institute of Medicine, moving from the National Research Council's Commission on Life Sciences. It was still operating in a largely mainframe computer and paper-based environment; the need to move to microcomputers and to computerize its various paper data files was clear, but funds to do so were not available. OTA at that time recommended core funding of $500,000 per year for a five-year period to allow the agency to address the pressing problems. Despite a recommendation from Congress that MFUA be **given the full $500,000** per year, they have never received more than a compromise level of $200,000 (and that much only in one year), and the payment schedule has been erratic. **Even with this minimal core funding, significant improvements have been wrought since 1988 (with plans for further progress awaiting adequate core funding), placing MFUA on much stronger footing.**

MFUA occupies a small but unique niche in U.S. biomedical research; should it cease to function, important research opportunities would be lost irremediably. The key core functions of maintaining the existing cohorts (including updating and documenting morbidity and mortality, and not just storing records) and carrying out pilot projects (but not general administrative overhead), which are central to the continued functioning of MFUA. cannot, given the realities of research grant budgets, be supported by project-specific finds or by any other IOM or NAS institutional finds. **Core funds should be part of government spending on biomedical research, and should not fall below the modest level of $500,000 per year for the foreseeable future (see table 1).** Within the biomedical research community. separate core support is accepted as a necessary expenditure for the maintenance of other specific research cohorts and is built into program budgets. The issue of transferring funds from the government to the private sector for such core activities rarely arises because virtually' all epidemiologic research is supported directly' by government (NIH) programs. The case of MFUA, as part of a private institution that is funded on a study-by-study basis, is different in this regard, making the issue of core support a more explicit one than it is in most other circumstances. There are some other examples, however. For instance the National Cancer Institute supports core activities, currently at a level of about $140,000 per year each, of a Swedish and a Danish cancer registry. in addition to funding specific studies using these two registries.

MFUA rosters are used by researchers funded by DoD, VA, and NIH, so it would be logical to turn to one or more of these agencies for permanent core funding (all three contribute in the current short-term core funding arrangement). The most appropriate mechanism for achieving a stable core finding situation is not obvious, however, and was not addressed by OTA. **The current situation, in which MFUA has not received the full amount promised it in most years, and receipt of at least a portion of those funds has been unpredictable, is unacceptable.**

TABLE 1: MFUA Minimum Core Funding Needs

Activity	Cost per year ($)
Maintenance of cohorts	
Twins	150,000
All other cohorts	10,000
Pilot and feasibility studies (4-5 per year)	160,000
Board meetings (2 per year	20,000
Portion of salary, benefits, overhead, etc.	130,000
Software unique to MFUA	5,000
Hardware unique to MFUA	25,000
TOTAL	**$500,000**