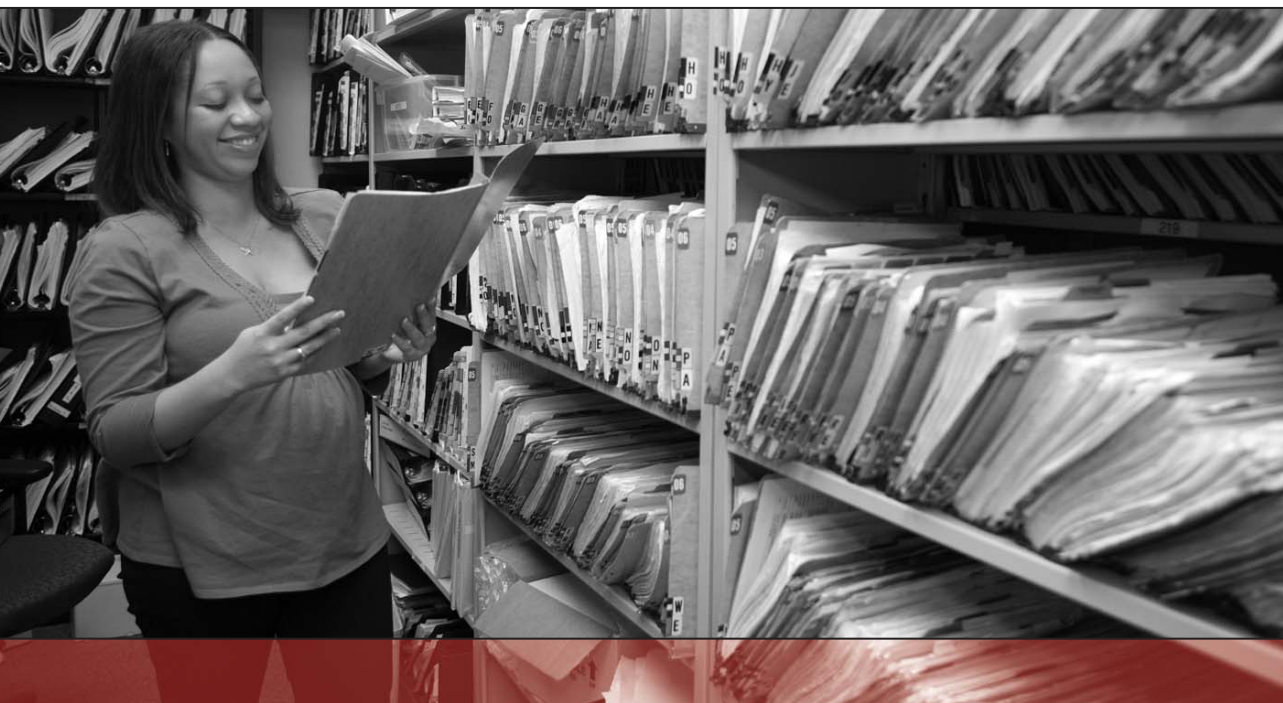


# HRSA CARE ACTION



MAY 2007

What Systems Are Available

What They Offer

How to Get Started

The Case for Investment

## SCALING THE MOUNTAIN: MANAGING DATA IN THE AGE OF ACCOUNTABILITY

In the United States today, providers deliver HIV/AIDS services in an environment of accountability—to funders, administrators, and consumers. Sophisticated electronic data systems are helping Ryan White Treatment Modernization Act\* grantees and providers flourish in this environment in ways that would have been impossible to imagine when the program began in 1990.

These systems have been created in the context of a national focus on electronic health records and information management, and they offer myriad benefits to those who operate and use them: the ability to process large quantities of clinical and support service data; improve quality management; and ease the burdens of reporting and oversight. Yet like all good things, they come at a price.

Electronic data systems can be expensive to build and maintain as well as difficult to understand. They require communities to grapple with

### DID YOU KNOW?

The 21st Century Health Information Act (H.R. 2234), introduced on May 10, 2006, authorizes the Secretary of Health and Human Services to make up to 20 3-year grants to regional health information organizations to develop and implement regional health information technology plans.

\*Formerly called the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act:  
<http://hab.hrsa.gov/treatmentmodernization>

### ONLINE RESOURCES

HIV/AIDS Bureau CAREWare Web site  
<http://hab.hrsa.gov/careware/>

Project ARIES Web site  
<http://projectaries.org/>

Houston CPCDMS Web site  
[www.hd.co.harris.tx.us/hivservices/cpcdms.html](http://www.hd.co.harris.tx.us/hivservices/cpcdms.html)

Regional Health Information Organization (RHIO) Glossary  
[www.calrhio.org/?cridx=515](http://www.calrhio.org/?cridx=515)

▶▶▶▶ Please visit our Web site at [www.hrsa.gov](http://www.hrsa.gov)



## DIRECTOR'S NOTES

*The quest for HIV-related data is almost as old as the AIDS epidemic. At first, we needed data to identify the population segments affected by the disease—and where it was likely to go next. As time passed, we needed data to help us plan, deliver, and evaluate services.*

*Data have been a tough issue in our field. Shortage of funds and well-founded concerns about anonymity and confidentiality have been two issues. Diverse administrative authorities and the disconnected nature of our health system have been two more.*

*Issues like these are part of the reason that we've sometimes felt like we were playing catch up where data are concerned. But, to me, at least, it's feeling that way less and less these days. Why? Because the power of data is being harnessed by grantees and providers in ways that we could hardly imagine 10 years ago.*

*We're still not where we need to be, of course, but in the past 5 years alone, the Ryan White community has made a quantum leap in the capacity to gather data. Moreover, the work of our providers and grantees exemplifies that our quest is not just to collect information; it is also to use it. Because when we do so wisely, we can improve lives—and save them, too.*

*Deborah Parham Hopson  
HRSA Associate Administrator for HIV/AIDS*

complex issues, such as confidentiality and privacy. And the process of implementing an electronic data system leads to the considerable task of answering hard questions, such as: What system is best for our local environment? Will it be flexible enough to meet future needs?

To understand how grantees and providers are addressing these and other questions, this issue of *HRSA CAREAction* offers the insights of officials who are using three diverse noncommercial systems. These systems were developed solely or primarily with Ryan White HIV/AIDS Program funds and are not intended to be an exhaustive review. Their experiences are instructive and demonstrate the rich possibilities that electronic data systems offer for meeting today's demands and those of the future.

### Data Management: Houston

The Houston Eligible Metropolitan Area (EMA) began planning for its customized Centralized Patient Care Data Management System (CPCDMS) in 1999. Implementation started in June 2000. Today, all the services provided in the EMA under Ryan White HIV/AIDS Program Parts A, B, and C (Titles I, II, and III) are recorded in the system. Clinical markers, such as viral loads, lab test results, and CD4 counts, are also recorded.

CPCDMS has undergone a number of modifications since it was introduced almost 7 years ago. Initially, software was installed on a desktop computer at provider sites and then synchronized to a single server at the EMA's grantee office. Data communication was facilitated through a point-to-point data link (i.e., a link between two computers, one at each location). Only the EMA had access to data, in contrast to today, when all providers have access to basic eligibility data. For data to be exchanged between a provider and the grantee, the initial version of CPCDMS required that its software application be running at both sites simultaneously.

In this earlier configuration, coordination between sites proved cumbersome. The system also required significant technical assistance and was expensive to support and maintain.

In 2003, the CPCDMS was reconfigured to run on the Internet, and staff and clients report that the new version is easier to use. "We don't

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Cover, staff member, the Detroit Medical Center/Wayne State University HIV/AIDS program; page 4, staff members, Brooklyn Hospital Center Program for AIDS Treatment and Health Center; and page 7, Hurricane Katrina damage outside Hattiesburg, MS. All photos © See Change.

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have to support a whole bunch of workstations and purchase a lot of hardware,” explains Charles Henley, manager of HIV services for Houston’s public health department. “Agencies need a high-speed Internet connection, but that is not an expensive requirement these days.”

In CPCDMS, data are recorded using a unique record number (URN). Names are not stored. The system has brought improvements both in the quality of care and reporting. Two full-time staff manage the database and provide technical assistance, and system management is supported with Ryan White HIV/AIDS Program funds.

## The ARIES System

The AIDS Regional Information and Evaluation System (ARIES) was a collaborative effort of the California Department of Health Services Office of AIDS, the San Diego and San Bernardino EMAs, and the Texas Department of State Health Services HIV/STD Epidemiology Division. A customized HIV/AIDS client case management system, ARIES was built with the support of Ryan White HIV/AIDS Program and State funds.

ARIES was launched in January 2005 in Texas, where providers funded through Ryan White HIV/AIDS Program Parts A through D (Titles I through IV) are mandated to

use the system for data reporting. Providers using other data applications—such as those in the Houston EMA—can import their data to ARIES, eliminating the need for double entry. In California, the San Bernardino and San Diego partners launched ARIES in December 2005; the launch at the State level took place in July 2006.

ARIES is Internet-based. Data are stored and administered centrally by the Texas and California Part B (Title II) grantees for their respective States. “The plan was for the three California partners to separately host ARIES with the systems interacting as little as possible,” according to Susan Sabatier, chief of the Care Research and Evaluation Section of the California Office of AIDS. “However, it became clear that hosting separate systems was not only redundant in terms of hardware and staff, but prevented us from getting the most out of ARIES.”

To support the people who use or will be using ARIES, California is implementing a training plan for approximately 150 service providers. The Part B (Title II) grantee in California has invited the seven California Part A (Title I) EMAs to adopt ARIES, by either joining the State’s installation or taking on the responsibilities and costs of running their own system, provided that it has the ability to interact with the State ARIES system for reporting purposes. Sabatier states, “We have a team

## DESIGNING A SYSTEM: IMPORTANT DESIGN AND IMPLEMENTATION ISSUES

### System Configuration

- ▶ Non-network: One stand-alone PC running on its own, serving one provider?
- ▶ Local area network: Multiple users in one system, as in a large clinic in one building?
- ▶ Wide area network/Internet: Multiple users connected to one central server?

### Storage of Personal Identifying Information

- ▶ Client names?
- ▶ Unique identifiers?

### Data Sharing

- ▶ None?
- ▶ Selected information only (e.g., service data) shared only with selected providers?
- ▶ All information shared with any provider that has a need to know?

### Other Features

- ▶ Report functionality: Will the system produce the CARE Act Data Report, custom reports, financial reports, and other required documents?
- ▶ Customizability: Is it easy to add unique fields, tests, and services?

### Personnel and Staffing

- ▶ Are information technology (IT) staff available to manage a networked system, routinely back-up data, upgrade software, and perform other operational tasks?
- ▶ Are there training resources to ensure that users understand all aspects of the system?



that's provided ARIES demonstrations and information to the EMAs; additionally, we've received great interest in ARIES from grantees outside of California, including Nevada, which recently decided to adopt ARIES."

Access to client-level data is a big issue in HIV care, and with the ARIES systems, the client chooses whether his or her data may be shared among providers. Sharing client-level data facilitates coordination of care, easier monitoring, and improved health outcomes.

Several system features protect client confidentiality. ARIES users are granted different levels of system access depending on their roles within an organization. Moreover, information related to substance abuse, mental health, and legal issues is never shared. In addition, many security features protect the names stored in the system. For example, information is encrypted during transmission and again in the central database.

## **CAREWare**

CAREWare is the most familiar system to many people in the Ryan White community because it was developed within the Health Resources and Services Administration (HRSA). The first version was released in 2000, and a major upgrade, using new software and database technology, was made available in 2005.

CAREWare is free and can run as a stand-alone application, over a local- or wide-area network, or the Internet. Running the system over the Internet allows a

network of users to link in real time to a central database containing unduplicated records. Like the ARIES and CPCDMS systems, such a configuration eliminates the need to export data from each provider to the central domain.

CAREWare can also be configured with disconnected providers (i.e., those not connected in real time over a network), who export data in batches on a regular basis to the central administrator, or with a combination of real-time and disconnected providers.

Currently, CAREWare is being used by more than 300 Ryan White grantees and providers—from small, community-based organizations to State and citywide networks. Its flexibility can be seen by looking at two different systems in Philadelphia and Oregon.

### ***CAREWare in Philadelphia***

In the Philadelphia EMA, all providers funded through Ryan White HIV/AIDS Program Parts A through D (Titles I through IV), except one Part C (Title III) program, are required to report data through the EMA data system. Providers are required to enter the data elements contained in the CARE Act Data Report (CADR) as well as locally required data elements specific to each service. For instance, all Part A-funded (Title I) medical providers are required to enter data related to predetermined variables (e.g., all visits, viral loads, CD4 counts, medications, gynecological care, hepatitis serologies and treatment, and testing for sexually transmitted infections).

At regular intervals, providers export client-level data (with identifiers removed) from their CAREWare dataset to the grantee for analysis. Analysis includes both routine process monitoring (i.e., number of clients, client contacts, and units of service) and client and system outcome monitoring. A key feature of the system is that client data are not shared among providers. The decision to implement this type of “disconnected” system was primarily the result of confidentiality concerns expressed within the community.

### CAREWare in Oregon

The Oregon Department of Human Services (ODHS), the State’s Ryan White HIV/AIDS Program Part B (Title II) grantee, was the first grantee to implement the network version of CAREWare. The system is a centralized network used by 20 case management providers and approximately 50 other users around the State (excluding the Portland EMA, which does not receive Part B funding).

“Two drivers for choosing the CAREWare system in 2001 were cost-effectiveness and the system’s ability to be implemented statewide,” says Annick Benson-Scott, HIV support services manager for ODHS, adding that “[Oregon] was familiar with the earlier version of CAREWare that could not run over the Internet,” which eased the transition to the network version.

The Oregon data system is being used exclusively by case managers. The system is credited with increased efficiency in monitoring service delivery to the State’s primarily rural, yet mobile, Part B client base. The focus of the system is on collecting service utilization data. The only clinical information currently reported through the system is viral load and T-cell count.

## Knowledge Is Power

Networked electronic data systems offer significant advantages in almost all facets of program management and service delivery. The grantees interviewed for this article concurred that the costs in time and money of implementing and maintaining electronic data systems are far outweighed by their benefits.

### Revolutionizing Quality Management

Data systems can serve as the virtual backbone of an organization’s quality management efforts. With unique client identifiers and real-time data entry, computerized information systems allow grantees to accurately track the number of clients being served, the services being utilized, demographic information, and extensive details about the quality of care.

“Essentially, Congress wrote into the CARE Act reauthorization of 2000 that grantees must have a quality improvement project so that they can do more than show that they wrote a lot of checks,” says Coleman Terrell, information services unit manager at the Philadelphia Department of Public Health’s AIDS Activities Coordinating Office.

He adds, “They need to show that things are getting better. It’s not enough to say we fund high-quality agencies. We must demonstrate that the clients are receiving high-quality services and are better off at the end of the day. This is the goal.”

To assess and improve the quality of services, Philadelphia developed a list of indicators for all its Ryan White HIV/AIDS Program services. The list on the following page provides a sampling of those indicators.

OVERVIEW OF PROFILED SYSTEMS					
Location and Software	Houston CPCDMS	California AIRES	Texas AIRES	Philadelphia CAREWare	Oregon CAREWare
Patient Identifier: name or URN*	URN	Name and URN	Name and URN	Name and URN	Name and URN
Ryan White HIV/AIDS Program components	Parts A-C	Parts A-C	Parts A-B	Parts A-D	Part B (case managers only)
Number of providers	25	51	92	75	20
Number of unique client records	13,000	9,541	21,593	13,000	1,400

\*Unique record number

**Case Management**

- ▶ Clients following up on referrals
- ▶ Case managers completing quarterly assessment of mental health history and treatment
- ▶ Case managers completing quarterly assessment of substance abuse history and treatment
- ▶ Case managers retaining clients in case management 6 weeks after intake
- ▶ Clients without medical care attending a medical appointment within 6 weeks of intake

**Medical Care**

- ▶ Clients receiving viral loads and CD4 counts consistent with Public Health Service (PHS) guidelines
- ▶ Clients receiving *pneumocystis carinii* pneumonia (PCP) prophylaxis as needed
- ▶ Clients with undetectable viral loads
- ▶ Women receiving Pap smears and colposcopies as clinically appropriate
- ▶ Clients receiving HIV medications consistent with PHS guidelines

Should a provider demonstrate performance below the standard for any indicator, a quality improvement project (QIP) is designed and implemented, thus allowing the provider to determine the causes of poor performance and take steps to improve it. The grantee is then able to monitor the implementation of each QIP and the progress made toward improvement.

The quality management benefits of computerized data systems are echoed by Benson-Scott in Oregon. "The data that we gather from providers in our system have helped us to identify quality issues among case managers and providers at large and to discern whether case management is being conducted by the standards in place at the grantee level."

In Texas and California, ARIES offers similar advantages. According to Darla Metcalfe, URS data manager with the Texas Department of State Health Services, "Using reporting features within ARIES, the agency's quality management committee identifies trends in the data that indicate the need for action. Agency-specific quality management data are reviewed at least once per quarter to check for missing and unknown data, incorrect service entries, entry timeline compliance, conflicting client information, and other primarily CADR

elements. Subcontractors are currently required to have fewer than 3 percent missing, unknown, incomplete, or incorrect data elements."

**Facilitating Efficient Reporting**

Automated data systems have brought an end to the weeks and months of sifting through mounds of papers, recalculating numbers, and checking data that often characterized report preparation in the pre-automated era. Now—with providers trained to use automated systems, with technical assistance available when problems inevitably arise, and with data available nearly instantaneously upon entry—reports can be generated with almost the flip of a switch. In addition, automated systems typically can generate reports for multiple needs, such as for city, State, or Federal officials.

**Reducing the Administrative Burden**

Data systems that are managed centrally, such as those belonging to the profiled grantees, allow providers to spend less time on writing reports and more time with their clients. Because the Oregon CAREWare application is centrally managed, for example, participating case managers are able to shift some of their data requirements onto grantees. Similar benefits have been found in Houston and with ARIES users.

According to Sabatier, "One of the immediate ways ARIES reduces the administrative burden, for both our providers and my staff, is that no longer will providers have to export their monthly client and service data from their computer, copy it on to a disk, package it, and send it in the mail to us. And we no longer have to open each package, virus scan the disk, upload the data into our database, do quality checks, work with the providers to correct any errors, then finally run statistical reports. With ARIES, once the providers enter the data, we can immediately run a quality check and generate reports."

**Monitoring Service Delivery**

Automated systems allow administrators to monitor an almost limitless number of service delivery markers. Because service delivery data are usually entered the day that the service is provided, problems are dealt with more quickly than in the past.

In addition to helping grantees, ARIES helps providers monitor their work. Each agency can designate goals related to number of service units, unduplicated clients, and spending per service. Agency administrators can use ARIES to generate reports showing whether those goals are being met.

### **Improving Planning and Allocations**

Electronic data systems provide data that allow planners to base resource allocation on actual usage patterns rather than outdated, and sometimes false, assumptions. The same data allow planners to examine whether services are reaching historically underserved populations or neighborhoods within their local communities. Because data systems allow grantees to identify what services are being used by specific subpopulations affected by HIV/AIDS, they can allocate resources more wisely, efficiently, and effectively.

### **Introducing and Sustaining a System: A “How To” for Grantees**

The systems used by the grantees in this article differ in design and, to some extent, in purpose. All grantees, however, took similar paths to get where they are today, which is instructive for those interested in using today’s technology to help meet their reporting, monitoring, and quality improvement needs.

### **Get Communities Involved in a Collaborative Process**

Interviewed grantees were unanimous that the most important element of success was the early and ongoing involvement of the Ryan White community in planning and implementation. They advise providers and grantees to take the following steps:

- ▶ *Listen carefully to constituents.* Gathering stakeholder input is crucial to achieving buy-in. This process will help ensure a common understanding and agreement about how the system will be designed and how it will affect the people it is meant to serve.
- ▶ *Reach consensus on all levels.* Before the system is underway, all stakeholders must be comfortable with how data will be used, tracked, transferred, secured, and held confidential.
- ▶ *Ensure that the system reflects community needs.* Because the community comprises several populations—from clients to case managers to administrators—address the issues that matter most to these unique populations and to the community as a whole.

### **Confront Confidentiality Concerns**

For people living with HIV/AIDS, confidentiality about HIV status has always been a major concern. The idea of entering personal health data and, in some cases, sharing it over an Internet system may produce anxiety and even cause clients to refuse to participate. Communities have adopted diverse solutions to deal with this issue.

In Philadelphia, data sharing among providers was not implemented because of strong confidentiality



### **MAKING THE CASE FOR DATA: FACT OVER SUPPOSITION**

After Hurricane Katrina, Houston became a refuge for evacuees. Within a day of the storm, the Houston EMA had used its data system to identify the geographic origins of HIV-positive hurricane victims, says Charles Henley of Houston’s public health department. The data showed that Houston had taken in just 167 of 3,000 HIV-positive evacuees from Louisiana. This information allowed HRSA to focus on identifying where the other evacuees had fled to provide assistance proportionately.

concerns in the consumer community. The EMA system was designed so that providers could input data but not share it with each other. The protection of client privacy was seen to far outweigh the advantages that accessing client-level data would offer providers.

In Houston, basic client eligibility data are shared among providers. The advantages are that data are available when clients present for services and that clients do not need to resubmit eligibility data continually. However, agencies can only access service data related to the services they provide.

In the Oregon and ARIES systems, clients decide whether to allow their personal data to be shared among providers. The Oregon system also shows when login attempts have been unsuccessful and potential users have been locked out of the system. Similarly, ARIES partners have instituted features to secure data, including “dual-factor authentication” for system access—a system in which the user is required to *know* something (login ID and password) and *have* something (a digital certificate installed on the user’s computer).

### **Make a Plan and Dedicate Resources**

Although goals and deadlines are important for an effective system rollout, bumps along the road are inevitable. Terrell advises grantees to develop a multi-year timeline but remain flexible with providers. He says, “The planning body has to ask itself, What will it take to sustain this system in the future?”

Key to a successful rollout is setting realistic goals—and then working hard to meet them. Grantees interviewed for this article all observed that a successful health information system depends on striking a balance between continual improvements over time and rewards early on. Grantees also underscored the need to remind people of the benefits they’ve gained. “It’s easy to forget where we’ve come from and how the system can help us get where we want to go,” says Terrell.

### **Address Technical and Funding Challenges**

Technical support is critical to data management systems, but providing it can be a major challenge—particularly predicting how much is needed and how best to deliver it. Philadelphia, where the system has extensive quality management applications, has five dedicated staff, whereas in Oregon, one employee spends just part of his time on network support.

By far the major challenge, however, is that regardless of size or complexity, all data systems represent a significant investment. This year, the Houston EMA budgeted \$150,000 for programming, development, and

management and \$160,000 for system maintenance—an investment that “more than pays for itself,” says Henley. This investment is less than in prior years, thanks in part to the significant level of online support.

## **Major Benefits From Major Commitments**

The experiences of interviewed providers yield several lessons for the HIV/AIDS community. Data systems can be designed in different but equally effective ways, and they all can yield major rewards. But their benefits come after large investments of time, money, and energy. Data management in the age of accountability is more than a technology-driven endeavor. It often mirrors HIV care itself—requiring the commitment and collaboration of the entire HIV services community. Collaboration cannot be gained through blind faith. It requires that concerns about confidentiality and changes in workloads be addressed.

Equally crucial is an honest analysis of the resources needed to develop and maintain the system and a candid discussion about the long-term requirements of time, money, and human resources to ensure that the system functions smoothly on a daily basis and grows appropriately over time.

Although the costs of an information system will diminish after installation, applications will always require ongoing investment for upkeep and modification. Moreover, we live in an age of ever-increasing attention to efficiency, growing HIV prevalence, rising costs, and scarce resources. The need for the management tools that data systems uniquely provide is only going to increase in the next decade. ◀▶

## **REAUTHORIZATION AND A NEW NAME**

In December 2006, President Bush signed the Ryan White HIV/AIDS Treatment Modernization Act of 2006. The “Ryan White CARE Act” is now referred to as “Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Modernization Act of 2006,” or the “Ryan White Program” for short. Individual grant programs are referred to as follows:

- ▶ Title I is now Part A (Title I)
- ▶ Title II is Part B (Title II)
- ▶ Title III is Part C (Title III)
- ▶ Title IV is Part D (Title IV)
- ▶ Special Projects of National Significance is Part F (SPNS)
- ▶ AIDS Education and Training Centers Program is Part F (AETCs)
- ▶ Dental Programs (Dental Reimbursement and Community-Based Dental Partnership) are Part F