Notes for remarks by John Adams of Elivery Solutions Inc. to the SARS Commission on November 19, 2003.

Good afternoon, Mr. Justice Campbell.

I am John Adams, President and CEO of Elivery Solutions. We are a management consulting firm specializing in change management to harness information technologies to improve performance of public and private organizations.

Part of my background relevant today is my nine years of service on Toronto City Council ending in the year 2000, including stints as Budget Chief, on the Toronto Board of Health and as a trustee of Canada's largest hospital, the University Health Network.

It is an honour to be presenting jointly today with Dr. McQuigge. In the audience today is my business partner, Robert Hollands, whose passion for using information technology to build a more intelligent health care system has infected at least myself and Dr. McQuigge. We are here today pro bono.

[slide #1 on theme]

My theme today is, "Emerging Best Practices for Early Detection of Infectious Disease Outbreaks: It's Time for Action in Canada."

SARS was and is to Canada, Ontario and Toronto what anthrax was to the United States: a genuine bio-threat. Our SARS experience – coming on top of earlier experiences of other outbreaks addressed by Dr. McQuigge -- demonstrates that it is too late and too expensive to wait for business-as-usual, paper-based reporting or to wait for confirmed diagnoses of emerging outbreaks of infectious disease before

taking nimble action to protect front-line health care providers, affected patients, contacts and the general public.

[slide #2: DARPA]

DARPA stands for the US Defence Advanced Research Projects Agency. This slide summarizes a framework for thinking about data sources for biosurveillance.

In crossing the continuum of detection from early to later, DARPA classifiies non-traditional data sources: environmental, animal and human behaviours; non-traditional medical sources: telephone complaints to health lines, ER visits, poison centres as well as the traditional clinical data – the gold standards for data.

Effective action against virulent pathogens requires early detection of emerging outbreaks. Early detection or, even better, very early detection, depends on automated data collection and computerized analysis of signs and symptoms such as :

- a spike in sales of over-the-counter, anti-diarrhea medication as an indicator of water-borne infections,

- a spike in lab tests ordered by different doctors (who may not immediately know what other doctors are facing), or

- a spike in suspicious symptoms and chief complaints presenting at one or several hospital ERs or walk-in clinics, where busy front-line staff may not notice the links among the patients.

No machine or IT system can replace the crucial role of the astute clinician in identifying suspicious or strange occurences that the clinician is aware of. Some suspicious clusters of signs and symptoms are not detectable by an eagle-

eyed health care profession working in a single setting. We can add to the intelligence of practitioners with the artificial intelligence of smart systems of automatic data collection, sharing and analysis.

The public and private sectors in health care have invested hundreds of millions of dollars in data systems such as hospital registrations, teletriage, pharmacy benefit systems, retail point-of-sale and management decision supports.

From an early detection point-of-view, we need to connect the dots – the electronic dots -- as quickly as possible and work hard to transform paper-based health records into useful electronic ones. There are examples of how this is being done not far from here.

In response to a proposal we initiated pre-SARS, in December 2002 the Ontario Ministry of Health and Long-Term Care retained to undertake a feasibility study of a potential pilot project in early warning of infectious disease outbreaks focused on patient visits to one or more hospital emergency departments. The final report of the feasibility study was delivered in the Spring of this year.

Our report, on our initiative and at no extra cost to the Government, went well beyond its scope of work to examine significant initiatives undertaken in the United States.

[slide #3 what others are doing? NYC conference]

To keep current in a field developing rapidly in the United States, last month we attended the second-ever conference on syndromic surveillance sponsored by the Centres for Disease Control, the New York City Department of Health and Mental Hygiene and the New York Academy of Medicine.

[slide #4: DC conference]

We have also paid attention to a conference held last week on "Syndromic Surveillance: Performance and Utility" by the American Medical Informatics Association. [slide: results – Wagner] I will try to summarize what we can and should learn from others.

[slide #5 NYC] This morning in New York City, like every morning since 1999 but expanded in scope in late 2001 (post 9/11 attacks and post anthrax attacks), the duty officer for New York City's public health surveillance unit logged on to their computer system and was automatically presented with a report highlighting any significant statistical anomalies from the following data from yesterday:

- chief complaints of all patient visits – about 8,000 -- to emergency departments in 40 hospitals
- all of the average 3,000 health-related calls to 911
- sales of 8,000 prescription drugs in a representative sampling of pharmacies
- sales of 40,000 over-the-counter products in a representative sampling of drug stores
- absenteeism of civic workers.

This early detection system is run by New York City at a yearly operating cost of about $1,000,000 USD to help protect its economy, its tourism, its health care workers and its 8,000,000 residents.

About once a week, this system turns up something that public health officials determine warrants a second look. Most prove to be innocent statistical anomalies, but not all. "Our system routinely picks up patterns that were never caught before," Dr. Don Weiss, who is director of communicable disease surveillance, told the New York Times this past April. "What is sobering is that almost every time we call a hospital to say, "Hey, your area has had a big increase of this or that, they're completely unaware of it."

The automated system consistently spots the onset of flu season earlier than traditional reliance on anecdotal reports from sentinel doctors.

Last fall, the system alerted public health to a wave of people seeking help for vomiting and diarrhea, symptoms that turned out to be early signs of an outbreak of a Norwalk-type virus. City officials got a few days' head start to warn doctors and nurses and paramedics to take extra care in handling contagious bodily fluids.

No one in Canada, Ontario or Toronto is collecting or analyzing this kind of information today for the protection of the public's health. We have work to do to catch up with best practices.

Westchester County – much like our York Region -- with its population of about 1-million people as a next-door neighbour of New York City launched its surveillance system on January 1st using multiple data sources and mostly internal technical talent. They call theirs CHESS for Community Health Electronic Surveillance System.

[slide #6: greater Washington]

Since 9/11, the greater Washington Area has seen a surveillance partnership between multiple local public health authorities and the US military which has made available its ESSENCE system. ESSENCE stands for Electronic Surveillance System for Early Warning of Community-based Epidemics. ESSENCE was first developed to help protect US military installations around the world from local community infections.

[slide #7: Pennsylvania & Utah]

In the wake of 9/11 and anthrax, the US was concerned about the safety of the 2002 Winter Olympics in Salt Lake City, Utah. A public health surveillance system developed at the

University of Pittsburgh was deployed immediately after 9/11 in parts of Pennsylvania. Subsequently it has been rolled out permanently across the State of Utah and Commonwealth of Pennsylvania. It is known as RODS for Real-time Outbreak and Disease Surveillance.

[slide #8 Web Interface of RODS]

This slide plots respiratory visits and symptoms by map of the 2002 Olympic sites around Sault Lake City, Utah. It takes a mouse click to change time frames or map characteristics.

[slide #9: RODS backgound (1)]

RODS was the first public health surveillance system to have the capacity to analyze data in real-time. It started with chief complaint information from patient visits to emergency rooms.

[slide#10: RODS background (2)]

Public health surveillance does not need identifying information on individuals. It is looking for emerging, unusual patterns or clusters.

[Slide #11: How RODS Works]

The existing IT system in a hospital emergency department captures key information on chief complaint at the time of registration. It takes four to eight hours of work by one hospital IT person to set up its system to share data with RODS, which in turn can share data and analysis with public health.

[Slide #12 web Interfaces]

This slide is an example of the types of high-level, accessible reports available to RODS users. This graphs hospital ED

registrations by the major syndromes during one week for across the entire state of Utah. It talks but one mouse click to switch from all counties to one specific county.

[Slide #13: RODS Technology Dissemination]

Veterans of medical technology have told me that it takes 10 years or more to widely distribute proven new technologies.

The RODS Laboratory at the University of Pittsburgh recognized that access to more kinds of relevant data was the big challenge. It began a data sourcing initiative in December 2002 known as the National Retail Data Monitor.

[slide 14: NRDM How it works (1)]

The National Retail Data Monitor is a public health surveillance tool that collects and analyzes over-the-counter point-of-sale data daily or, in some cases, hourly.

As of last month, in less than one year, there are 18,000 retail stores and pharmacies from major retail chains that are participating or have agreed to participate.

[slide #15: How NRDM works (2)]

It has 223 system users in health departments across 33 US states, the District of Columbia and the CDC that receive daily aggregate data in maps and graphs. Several regions, including New York City and Washington, D.C., receive aggregate raw data which they can view and analyze through their own interfaces.

[slide #16: NRDM Surveillance Categories]

The project is a collaboration with the food and drug retail industry, state and local health departments and the CDC. It has grown into a high-priority national project.

The raw data is provided by the participating retail chains FREE and the aggregate data is provided FREE to public health authorities through a secure web-based user interface.

[slide #17: OTC sales Pennsylvania]

This slide shows the point-and-click ease of use to eyeball sets of data. It tracks OTC sales across the state of Pennyslyvania showing a three-week period. It takes just a click or two to display different sets of data for different matters of interest.

The immediate project goals for NRDM are:

- increase market share coverage to 70%
- get to Universal Product Code (UPC) data granularity
- decrease data feed time to close to real time (now mostly batched every 24 hours)
- see the data are reviewed by public health daily
- create a sustainable organizational model.

[slide #18: data analysis – electrolytes Philadelphia]

This slide shows easy graphic representation of data. A quick glance providing you are not colour blind identifies anomalous areas.

The RODS software is available on the Internet as open source.

[slide #19: Big City coverage]

Data from four major chains provides substantial market share for surveillance data in the 20 largest US cities. In New York City, for example, a local retail chain supplies data to NYC public health surveillance in addition to the feed of data from RODS NRDM project. They estimate that more than 80% of the pharmacies and drug stores in New York City are providing OTC sales data.

In Canada today, no pharmacy or drug store is providing this kind of data to any public health authority for disease surveillance. The IT infrastructure is in place and Canadian retailers, like their US counterparts, already share this data with trade information services. Some data has been shared for public health research purposes well after the fact of an outbreak, as we have seen from Dr. McQuigge's presentation. We have work to do here in Canada to make OTC pharmacy data available every day to public health officials.

[slide #20 on public health law]

Only this week did I learn that three US states – Wisconsin, Utah and Michigan – have recently updated their public health laws to require pharmacists and pharmacies to report on unusual increases in prescriptions dispensed and non-prescription products sold which are of interest from a public health surveillance perspective.

[slide #21: Results of Chief Complaints and OTC]

We met the Director of RODS last month and this slide is the title of one of his presentations to the conference last week in Washington, D.C. Dr. Michael Wagner and his team are very interested in helping to develop a similar set of initiatives in Canada. Afterall, we use the exact same Universal Product Codes in the retail business. I was in touch with the RODS Administrative Director this week and they have offered to come to meet with any interested parties in Canada. All they request is reimbursement for travel expenses.

{{ There are many other examples of emerging electronic public health surveillance systems in larger and smaller US communities too numerous to elaborate in the time available today.

By way of contrast and comparison, the World Health Organization gathers epidemic intelligence from informal sources as well as formal government-to-government channels. WHO says many initial outbreak reports originate in the electronic media and electronic discussion groups. The Global Public Health Intelligence Network (GPHIN) developed for WHO in partnership with Health Canada, is a semi-automated system that continuously searches key web sites, alert networks, newswires and online media sites, public health email services and websites of national governments, public health institutions, NGOs and specialized discussion groups to identify early warning information about epidemic threats and rumours of unusual disease events.**}}**

I am well aware, Mr. Justice Campbell, that as a result, in no small measure, of your work on a previous inquiry in the wake of the Paul Bernardo serial killings that every police force in Ontario is using a powerful electronic tool to better manage investigations of major crimes.

[slide #22: important distinctions]

In the case of SARS for itself and as proxy for other infectious outbreaks, let us distinguish clearly among three separate needs for better information solutions. SARS taught us lessons about detection, case management and contact management. They are different functions. We understand the Ontario Government plans to implement in stages the public health software known as iPHIS developed by Health Canada for case management. We also understand that there is a new plan to add a module to iPHIS for contact management.

We know that iPHIS has no component for early detection and we are not aware of any plan to add that functionality to iPHIS. There is a gap concerning an early detection solution.

[slide #23 on findings & recommendations]

We urge you to include in your work and report a series of findings and recommendations to advance the case for electronic early detection of infectious disease outbreaks.

1) Ontario and Canada lack but need an electronic, early detection system for public health.
2) There is a need for a clear mandate and leadership.
3) Funding is required for early detection data collection, data sharing and analysis.
4) Laws are needed to promote and require data sharing for early detection.

[slide #24: Time for Action in Canada]

Upon implementation, such recommendations will save many lives, prevent much personal suffering, better protect the public and health care workers and reduce the other serious consequences of epidemics and pandemics.

When public health practitioners have the equivalent, powerful tools as police officers to detect outbreaks and to manage cases and contacts, then we will have a good news story to tell about best practices in early detection of infectious disease outbreaks in Canada.

Thank you for your time and attention.