MARYLAND
HEALTH CARE
COMMISSION

STRATEGY FOR IMPLEMENTING ELECTRONIC ADVANCE DIRECTIVES & MOLST FORMS

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An Information Brief

Health Information Exchange Challenge Grant

Craig P. Tanio, M.D., Chair

Ben Steffen, Acting Executive Director

Commissioners

Craig P. Tanio, M.D., Chair
Chief Medical Officer
JenCare Neighborhood Medical Centers

Garret A. Falcone, NHA, Vice Chair
Executive Director
Heron Point of Chestertown

Reverend Robert L. Conway
Retired Principal and Teacher
Calvert County Public School System

John E. Fleig, Jr.
Director
United Healthcare

Helene Grady
Associate Dean for Finance and Administration
Johns Hopkins University School of Nursing

Kenny W. Kan, CPA,FSA & CFA
Senior Vice President/Chief Actuary
CareFirst BlueCross BlueShield

Robert Lyles, Jr., M.D.
Medical Director
LifeStream Health Center

Barbara Gill McLean, M.A.
Retired, Senior Policy Fellow
University of Maryland School of Medicine

Kathryn L. Montgomery, Ph.D., RN, NEA-BC
Associate Dean, Strategic Partnerships & Initiatives
University of Maryland School of Nursing

Marilyn Moon, Ph.D.
Vice President and Director, Health Program
American Institutes for Research

Darren W. Petty
Vice President
Maryland State and DC AFL-CIO
General Motors/United Auto Workers

Glenn E. Schneider, MPH, BS
Chief Program Officer
The Horizon Foundation

Adam J. Weinstein, M.D.
Medical Director
Nephrology and Transplant Services
Shore Health System

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Executive Summary

Advance health care directives (advance directives) enable a person to appoint a health care agent to make treatment decisions and/or to provide specific instructions regarding potential treatments so that health care providers can administer care in accordance with the patient's choice. A living will is a more individualized and customized form of an advance directive. These legal documents allow patients to inform future medical care decisions even after becoming incapacitated. Advance directives typically become effective when a patient is no longer able to articulate medical decisions, such as in a comatose or terminal state. Enabling advance directives to be available electronically at the time and place of care could help ensure that a patient's wishes are known and honored. State law allows for the Maryland Department of Health & Mental Hygiene (DHMH) to establish an advance directives registry, subject to the availability of funds; funding is currently unavailable to support this initiative.[1]

Medical Orders for Life Sustaining Treatment (MOLST) forms are another means used to document a patient's treatment preferences. A MOLST form is a standardized medical order form that is valid across all health care facilities and replaces the Maryland Institute for Emergency Medical Services Systems *Do-Not-Resuscitate* form.[2] This form is a two page order, generated by a physician, indicating which medical treatments a patient desires or does not desire. It is valid across the continuum of care, and the details included on the form remind both patients and providers of available options for end of life treatment. Twelve states have implemented and about 25 other states are developing a MOLST or comparable form.

The Maryland General Assembly enacted a law in 2011 that requires long-term and post-acute care providers, as well as hospitals in certain situations, to create and maintain the MOLST form for patients under their care.[3] Maryland law stipulates that a copy of the MOLST form must be kept in the patient's medical record, accompanies the patient when the patient is transferred to a health care facility, and is given to the patient or health care agent within 48 hours of completion or sooner if the patient is transferred.[4]

In 2011, the Office of the National Coordinator for Health Information Technology awarded the Maryland Health Care Commission (MHCC) roughly $1.6 million to pilot the electronic exchange of clinical documents between paired long-term care facilities and hospitals through the statewide health information exchange (HIE). Funding for this pilot also calls for Maryland to plan for and test the availability of electronic advance directives and MOLST forms. A focus group[5] was

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[1] *Health - Advance Directives – Registry –Drivers' Licenses and Identification Cards,* Senate Bill 236 of 2006. Available online at: http://mlis.state.md.us/2006rs/bills/sb/sb0236e.pdf.

[2] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.

[3] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.

[4] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.

[5] Participants included representation from the Department of Health & Mental Hygiene; the Maryland Institute for Emergency Medical Services Systems; the AARP; the Health Facilities of Maryland; emergency room physicians and Chief Information Officers of Maryland acute care hospitals; the Commission on Aging; the Hospice and Palliative Care Network of Maryland; MedChi, the State Medical Society; health systems; and long term care facilities. See *Acknowledgements*.

convened to deliberate on the technical and policy challenges related to electronic advance directives and MOLST forms. The focus group proposed the following recommendations:

1. **Create a patient managed registry for advance directives.**

   Patients can make their own health documents available to treating providers via the statewide HIE by using a personal health record (PHR) system connected to the statewide HIE. In general, a PHR is a tool that enables patients to store, reference, manage, and share their health information electronically. Patient controlled PHRs would allow patients using a PHR tethered to the statewide HIE to enable advance directives to be queried by providers with access to the statewide HIE.[6] This method aligns with existing Maryland regulation that defines the requirements for an advance directives registry.[7] COMAR 10.23.10, *Advance Directive Registry*, specifies the DHMH may provide for the registry either directly or on a contractual basis with a third party.[8]

   The implementation cost of a patient managed registry tethered with the statewide HIE is about $92,000 and roughly $101,000 annually to maintain.[9] The registry would require about one year to procure, integrate with the statewide HIE, test and make public.

2. **Develop a registry for electronic MOLST forms.**

   Establish an electronic MOLST registry (registry) that is accessible via the statewide HIE. Providers required to generate a MOLST form upon discharge for defined populations should be required to submit this information electronically to a registry maintained by the statewide HIE. Documents in the registry would be query-able by providers using a secure web portal. Exclusions for electronic registry submission requirements would apply to providers with insufficient Internet access or under specific circumstances.[10]

   Changes to statute would likely be required to implement a registry for electronic MOLST forms and to require all MOLST forms to be submitted to the registry. House Bill 82, *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, from the 2011 legislative session, specifies that MOLST forms may be transferred electronically when consistent with the instructions for use of the form.[11] Additionally, statute and/or regulations should be modified as appropriate to require that when a MOLST form is signed and copied to a patient chart, a copy must also be sent to the registry.

   The implementation cost of a registry linked to the statewide HIE is about $252,000 and roughly $500,000 annually to maintain.[12] Once the regulatory process is completed and funding secured, the development time for a registry is about one year, which includes technology procurement, integration activities, testing and roll-out.

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[6] The Chesapeake Regional Information System for Our Patients (CRISP).
[7] COMAR 10.23.01, *Advance Directive Registry*. Available at: http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.23.01.*.
[8] COMAR 10.23.01, *Advance Directive Registry*. Available at: http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.23.01.*.
[9] For line item budget projections please see the *Appendix*.
[10] An Exceptions Committee will be established by the MHCC and CRISP to develop policies around waiver requests.
[11] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.
[12] For line item budget projections please see the *Appendix*.

Limitations

The information contained in this document is limited to the contributions made by participants of the focus group. A clinical workflow analysis associated with implementing the recommendations was not included in the work effort. This information brief does not address workflow changes and costs associated with hospitals or ambulatory practices in adopting the recommendations.

Introduction

Health information technology provides an opportunity to enhance the availability of advance health directives (advance directives) and Medical Orders for Life Sustaining Treatment (MOLST) forms by enabling information to move electronically, efficiently and seamlessly, across unaffiliated systems. Advance directives include information that is not necessarily included on the MOLST form, such as the appointed health care agent the patient would like to make medical decisions on their behalf if they are no longer able to make their own decisions. The use of electronic advance directives and eMOLST forms requires a commitment on the part of providers and patients.

Advance directives allow a patient to appoint someone to make health care decisions in the event that they become incapacitated, and permit providers to administer care in accordance with the patient's previously expressed wishes. Completion of these documents promotes advance care planning. Enabling these documents to be available electronically as part of a patient's health record could help to ensure that advance directives are more readily available at the time and place of care.

MOLST forms allow a patient's preferences to be transformed into actionable medical orders. Patients with serious medical conditions, who wish to avoid receiving any or all life-sustaining treatments, reside in long term care facilities and/or have a terminal illness, are generally the segments of the population for whom MOLST forms are maintained. The completion of the form is based on a conversation between the patient, the patient's health care agent/power of attorney, and the provider, and ensures shared, informed medical decision-making.

Health Information Exchange

The statewide health information exchange (HIE)[13] can help to facilitate the availability of advance directives by enabling the electronic documents to be accessible through the statewide HIE. In general, HIE helps to deliver the right clinical information to the right place at the time of care, safely and securely. Maryland has made significant progress in establishing an infrastructure for statewide HIE. As of December 2011, 48 hospitals, including all 46 acute care hospitals in the state and two specialty hospitals, are sharing data with the statewide HIE. The statewide HIE plans to connect the more than 5,000 physician practices and 235 nursing homes in Maryland to enable information sharing. In 2011, the Maryland Health Care Commission (MHCC) received roughly $1.6 million in funding from the Office of the National Coordinator for Health Information Technology (ONC) to pilot the electronic exchange of clinical documents, coupling six pairs of long-term care facilities and nearby hospitals through the statewide HIE, and to develop the technology and policy framework for electronic advance directives.

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[13] The Chesapeake Regional Information System for Our Patients (CRISP)

Advance Directives and MOLST Forms – A Maryland Update

For many years, various stakeholders have been interested in increasing the availability of advance directives for Marylanders. During the 2005 legislative session of the Maryland General Assembly, House Bill 1004, *Public Power of Attorney – Health Care Decisions*, proposed establishing a statewide registry for advance directives that consist of a power of attorney for health care decision documents.[14] Though the bill did not pass, a comprehensive report on the possibility of a registry was developed, and in 2006 a statute was enacted directing the Department of Health and Mental Hygiene (DHMH) to build an advance directives registry, subject to the availability of funds.

Senate Bill 236, *Health – Advance Directives – Registry – Drivers' Licenses and Identification Cards*, from the 2006 legislative session enabled the adoption of regulation to ensure efficient operation of an advance directives registry.[15] COMAR 10.23.01, *Advance Directive Registry*, describes the attributes of the planned registry. The regulation anticipates either a paper-based or electronic registry of all advance health care planning documents that will be accessible 24/7. The regulations stipulate a fee of $10, to be paid by the patient, provider or power of attorney, for each added or amended document logged to the registry. Included in the regulation are provisions for outreach and education to inform Marylanders of the registry and its benefits. The DHMH may provide for the registry either directly or on a contractual basis with a third party.[16]

MOLST forms are based on a patient's treatment preferences. A MOLST form is a medical order signed by a licensed physician or nurse practitioner and replaces the Maryland Institute for Emergency Medical Services Systems Do-Not-Resuscitate (EMS/DNR) form, although existing EMS/DNR orders will remain valid.[17] The MOLST form will consolidate important information into orders that are valid across the continuum of care; standardize definitions and remind patients and providers of available treatment options; and increase the likelihood that a patient's wishes regarding life-sustaining treatments are honored throughout the health care system.

Concurrent to the development of COMAR 10.23.01, House Bill 82, *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form* (HB 82) was under development. HB 82 was signed into law during the 2011 General Assembly and requires the DHMH, the Maryland Institute for Emergency Medical Services Systems and the State Board of Physicians to develop a MOLST form and instructions for its completion and use.[18] Upon completion of the form, a copy must be given to the patient or authorized decision maker within 48 hours or sooner if the patient is discharged or transferred. Beginning in 2012 (the exact timing has not yet been determined), certain health care organizations such as hospitals, nursing homes, hospices, and home health agencies will be required by regulation to complete or update a MOLST form for patients during a transition of care.

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[14] House Bill 1004, *Public Power of Attorney – Health Care Decisions*. Available at: http://mlis.state.md.us/google_docs$/2005rs/bills_noln/hb/fhb1004.pdf.

[15] *Health - Advance Directives – Registry –Drivers' Licenses and Identification Cards,* Senate Bill 236 of 2006. Available online at: http://mlis.state.md.us/2006rs/bills/sb/sb0236e.pdf.

[16] COMAR 10.23.01, *Advance Directive Registry*. Available at: http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.23.01.*.

[17] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.

[18] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.

In the fall of 2011, the MHCC convened a multi-stakeholder advance directives focus group (focus group)[19] to evaluate the technology and policy challenges and propose solutions to enabling electronic advance directives and MOLST forms. The focus group agreed that a phased approach to broad exchange of electronic advance directives and eMOLST forms would enable widespread adoption and use of these documents.

Advance Directive Initiatives in Other States

A small number of states have taken various approaches to making advance directives more readily available at the point of care. Some of these approaches are paper-based and, in the view of the focus group, not cost-effective or scalable. The focus group paid particular attention to the three identified states whose registries are tied to HIE initiatives: Oregon, New York and Virginia. Below are notable approaches from these states as it pertains to advance directives.

Oregon

Oregon has legislation similar to Maryland's MOLST law that has been in effect for several years. It is based on the Physicians Orders for Life Sustaining Treatment (POLST), which has since become a national initiative. In Oregon, emergency responders are trained to look for the brightly colored POLST form. Oregon decided to make the form bright pink so it would be easier to distinguish from white paper in an emergency. Patients are advised to keep their own copy of the POLST form in an accessible location; if it is not easily found, the registry serves as a backup. Oregon regulations mandate that the physician who signs a POLST form send it to the registry unless a patient opts out of participation in the registry. As of March 2011, after about a year and a half of operation, about 50,000 POLST forms from are available in the registry.

New York

New York has also made progress on an electronic approach to advance directives. The state has a MOLST law similar to Maryland's. The HIE in Rochester has a patient portal; this is primarily because the HIE requires patients to opt-in to participate so that their data can be exchanged. The patient portal allows users to upload advance directives documents. This approach places the burden on the treating provider to interpret documents and determine the usability of documents. It is up to the patient to decide which documents to upload, and there is no independent validation or quality control. Also, proxies and caregivers may not upload or manage documents on behalf of others. Patient identity proofing poses a challenge. To date, use of the registry has been minimal.

Virginia

Virginia recently launched its own patient managed advance directives registry, overseen by the Virginia Department of Health. The registry is a secure website that allows Virginians to create a free account and upload scanned care planning documents. Virginians can share access to these documents using a five-digit PIN of their choice. They can also print and carry a card which alerts others to the existence of documents in the registry. Currently, Virginia does not have a mechanism to validate the identity of any user of the registry. The state plans to connect the registry with the HIE sometime in the future.

[19] For a list of focus group participants, see *Acknowledgements*.

Recommendations

The focus group developed recommendations for a framework for storing and exchanging advance directives and MOLST forms electronically in Maryland to achieve widespread interoperability. The focus group identified a number of challenges associated with the current, paper-based paradigm for advance directives and MOLST forms, including: the likelihood of disconnected care across multiple settings as patients travel between health care facilities, the paper-based nature of the process itself; the existence and dissemination of documents that are not up-to-date or may not reflect current wishes. The focus group sought to address as many of these challenges as possible in the following recommendations.

1. **Create a patient managed registry for advance directives.**

   Patients can make their own health documents available to treating providers via the statewide HIE by using a personal health record (PHR) system connected to the statewide HIE. In general, a PHR is a tool that enables patients to store, reference, manage, and share their health information electronically. Patient controlled PHRs would allow patients using a PHR tethered to the statewide HIE to enable advance directives to be queried by providers with access to the statewide HIE.

   This method aligns with existing Maryland regulation that defines the requirements for an advance directives registry.[20] COMAR 10.23.10, *Advance Directive Registry*, specifies the DHMH may provide for the registry either directly or on a contractual basis with a third party.[21]

   A patient managed registry tethered with the statewide HIE will cost about $92,000 and roughly $101,000 annually to maintain.[22] The registry would require about one year to fully implement.

2. **Develop a registry for electronic MOLST forms.**

   Establish an electronic MOLST registry (registry) that is accessible via the statewide HIE. Providers required to generate a MOLST form upon discharge for defined populations should be required to submit this information electronically to a registry maintained by the statewide HIE. Documents in the registry would be query-able by providers using a secure web portal, which is presently available to providers free-of-charge and being utilized in numerous hospitals, long term care facilities, and outpatient settings. Exclusions for electronic registry submission requirements would apply for providers with insufficient Internet access and under certain circumstances.[23]

   Prior versions of the electronic MOLST (eMOLST) forms would be archived and indicated inactive, only one version per identity would be considered current. Providers could submit the eMOLST form to the registry through a variety of options, such as: using an EHR of a

[20] COMAR 10.23.01, *Advance Directive Registry*. Available at: http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.23.01.*.

[21] COMAR 10.23.01, *Advance Directive Registry*. Available at: http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.23.01.*.

[22] For line item budget projections, please see the *Appendix*.

[23] An Exceptions Committee will be established by the MHCC and CRISP to develop policies around waiver requests.

participant in the statewide HIE; through the statewide HIE secure portal; or through a secure message from a provider.[24] eMOLST forms submitted to the statewide HIE will be stored in a repository, where they can be queried.

Changes to statute would likely be required to implement a registry for eMOLST forms. House Bill 82, *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, from the 2011 legislative session specifies that MOLST forms may be transferred electronically when consistent with the instructions for use of the form.[25] Relevant statue and/or regulations should be modified as appropriate to require that when a MOLST form is electronically signed and copied to a patient chart, a copy must also be sent to the registry. Copies in the registry should be legally considered the current copy by any treating provider.

An eMOLST registry linked to the statewide HIE will cost about $252,000 in startup costs and roughly $500,000 annually to maintain.[26] The development time is about one year, which includes procuring the technology and moving into a production environment.

The focus group generally agreed that advance directives and MOLST forms should be available electronically to assist providers with certain health care decisions. Electronic patient managed advance directives and eMOLST forms offer improvement over what exists today, which is a manual system that has many inefficiencies.

Remarks

The discrepancy between what care patients who are nearing the end of life want and what they receive are often a result of inadequate communications among the patient, the family, and the provider. Electronic advance directives and eMOLST forms can express treatment preferences in a way that can be readily understood and followed by members of the health care team in all settings of care and prevent potential confusion among families and providers. The statewide HIE offers a viable solution to enable choices about end of life care to be clearly communicated. The technology provides secure access to a patient's information regardless of the patients or providers location, while retaining a patient's privacy. Questions about medical care at the end of life are important to deal with head on; the benefits of implementing technology to support advance directives and eMOLST forms generally outweigh the cost.

[24] The statewide HIE is currently establishing a secure messaging infrastructure based on the Direct standard. Direct messaging is a secure method for exchanging health information electronically across various information technology systems – a simple, cost-effective mechanism to transport patients' protected health information to known, trusted recipients over the Internet.
[25] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.
[26] For line item budget projections, please see the *Appendix*.

Acknowledgements

The MHCC appreciates the involvement of all the individuals who participated in the focus group. The high level of enthusiasm among the participants regarding the potential benefits in care delivery by making available electronic advance directives and eMOLST forms is laudable. The MHCC thanks the Chesapeake Regional Information System for Our Patients, as well as Mr. David Finney and Ms. Dana Voss from Audacious Inquiry for their assistance in completing the work associated with the focus group and developing implementation plans.

Richard Alcorta
Maryland Institute for Emergency Medical Services Systems

Paul Ballard
Assistant Attorney General
Maryland Department of Health and Mental Hygiene

Craig Behm
MedChi Network Services

Bridget Carver
Greater Baltimore Medical Center

Christine Crabbs
Hospice and Palliative Care Network of Maryland

James Del Vecchio
Holy Cross Hospital

Holly R. Dahlman
Green Spring Internal Medicine, LLC

Tammy Duell
Commission on Aging

Carol Eckerl
Genesis HealthCare

Justine Kellar
Greater Baltimore Medical Center

Margaret Koenig
Genesis HealthCare

Mary Kraaij
American Association of Retired Persons

Traci La Valle
Maryland Hospital Association

Jeff Landsman
Erickson Living, Oak Crest

Peggy Leonard
Genesis HealthCare

Courtney Marbley
Greater Baltimore Medical Center

Nicole McCann
Johns Hopkins Institutions

Patricia Tomsko Nay
Maryland Department of Health and Mental Hygiene

Joann Parr
Greater Baltimore Medical Center

Joe Petrizzo
Commission on Aging

Michele Phillips
Greater Baltimore Medical Center

Jody Porter
Greater Baltimore Medical Center

Bill Russell
Office of the National Coordinator

Margaret Semancik
LifeBridge Health

Sarah Sette
Maryland Institute for Emergency Medical Services Systems
Office of the Attorney General

Tressa Springmann
Greater Baltimore Medical Center

Patty Stehle
Health Facilities Association of Maryland

Pat Zeller
Johns Hopkins University

Appendix: Line Item Budget Projections

Patient Managed Advance Directive Registry

The implementation cost of a patient managed registry tethered with the statewide HIE will cost about $92,000 and roughly $101,000 annually to maintain. Operational costs will increase to $130,600 in year three due to additional patient identity proofing associated with increased participation. Below are projected line item costs for the patient managed advance directive registry.

Activity	Implementation $	Operation Year 1 $	Operation Year 2 $	Operation Year 3 $	Notes
PHR License	50,000	5,000	5,000	5,000	*Pricing modeled on a PHR currently integrated with the statewide HIE's core technology vendor in another implementation*
Patient Identity Proofing	-	1,000	10,000	50,000	*Variable: estimate of $1 per transaction; volume estimated*
Rollout and Training	97,200	-	-	-	*½ PM*
Support and Maintenance	-	63,000	63,000	63,000	*½ FTE*
Operator Overhead	19,440	12,600	12,600	12,600	*20% of direct costs*
Challenge Grant Contribution	(75,000)	-	-	-	
Total Cost	**91,640**	**81,600**	**90,600**	**130,600**	**349,440**

eMOLST Registry

The implementation cost of an eMOLST registry linked to the statewide HIE is about $252,000 and roughly $500,000 annually to maintain. Below are projected line item costs for the patient managed advance directive registry.

Activity	Implementation $	Operation Year 1 $	Operation Year 2 $	Operation Year 3 $	Notes
Development and Integration	200,000	20,000	20,000	20,000	
Infrastructure	40,000	10,000	10,000	10,000	*Hardware, hosting, etc.*
Rollout and Servicing Direct	200,000	20,000	20,000	20,000	*Direct secure messaging is expected to be the primary transport mechanism for MOLST forms*
Rollout and Training	135,000	-	-	-	*½ PM for 12 months*
Support and Maintenance	-	126,000	129,780	133,673	*1 FTE*
Support to Accept Faxes	-	252,000	259,560	267,347	*2 additional FTE; this could be excluded or phased out over time*
Operator Overhead	27,000	79,600	81,868	84,204	
Challenge Grant Contribution	(150,000)	-	-	-	
HIE Direct Contribution	(200,000)	(20,000)	(20,000)	(20,000)	*CRISP is funding the Direct rollout*
Total Cost	**252,000**	**487,600**	**501,208**	**515,224**	**1,756,032**

David Sharp, Ph.D., Director

Center for Health Information Technology

4160 Patterson Avenue

Baltimore, MD 21215

Phone: 410-764-3460

Fax: 410-358-1236

mhcc.dhmh.maryland.gov