

February 5, 2014

TO: REMTAC

BY: Dawn Brantley, HRPDC

RE: Electronic vote on continuation of ReadyHR Registry Tool

Dear REMTAC Members,

At the January 28, 2014 meeting, The Special Needs Subcommittee presented its recommendation to discontinue the ReadyHR Registry to REMTAC. Due to the time, effort, funding, and potential liability involved with HIPAA, the Special Needs Subcommittee has reexamined the ReadyHR Registry tool and has determined that the registry tool is ineffective as a planning tool, too high risk for HIPAA liability, not cost effective, and not the most effective use of time and effort. **The Special Needs Subcommittee voted to recommend discontinuing the Registry tool by a vote of 8-3 from the voting members; 14-4 all members present.** Out of seven emergency managers present for the vote, three voted to continue the program.

The Special Needs Subcommittee asked REMTAC to make a decision on the continuation of the ReadyHR Registry based upon a recommendation from the Special Needs Subcommittee. The Special Needs Subcommittee had invited and encouraged all REMTAC members to attend the January Subcommittee meeting to discuss the topic in detail. After discussion about the Registry at the REMTAC meeting, some emergency managers did not feel comfortable making a decision at the meeting and requested additional information. The committee decided to conduct an electronic vote and allow two additional weeks to give emergency managers time to review information previously provided on the topic. **We strongly encourage you to consult your locality's legal department.** Your legal department will ultimately be responsible for defending the decision. We are very willing to discuss this issue with your legal department.

Voting instructions are as follows:

All votes must be received by Friday, February 21, 2014 at 4pm.

Click on this link and complete all fields and questions:

<http://survey.constantcontact.com/survey/a07e8w2sgw0hr9mkbue/a001hrayz2zv/questions>

Votes will be tallied on the following Monday and the results emailed by close of business.

Liability

According to the HRPDC attorneys, Wilcox & Savage, the HRPDC is a business associate under HIPAA (45 CFR Parts 160 & 164, p.5570). The HIPAA Omnibus Rule, which went in to effect in September 2013, extended and increased enforcement of business associate (BA) compliance and made BAs directly liable for HIPAA violations. Because of this new ruling, the HRPDC has been working with Hughes VPO to become HIPAA compliant as a business associate.

During this process it was determined that the registry may also create liability for the localities under HIPAA as business associates. This would not apply to emergency management agencies that are covered entities or to emergency management agencies in localities that do not bill for EMS/ambulance. Based on information received and unofficial research conducted, it is believed that the jurisdictions fall under the following categories:

- Covered Entity Agencies
 - York County
 - Williamsburg
 - Franklin
 - Suffolk
 - Chesapeake
 - Newport News
 - Poquoson
 - Portsmouth
- Agencies Not Covered by HIPAA
 - Virginia Beach
 - Surry
 - Gloucester
- Business Associate Agencies
 - Hampton
 - Isle of Wight
 - James City County
 - Norfolk
 - Southampton County

Wilcox & Savage, the HRPDC attorneys, determined that there would be **no liability** to the HRPDC or the jurisdictions for discontinuing the registry as long as registrants were notified.

Cost of Program

The **annual cost** of maintaining and operating the ReadyHR Registry is **approximately \$39,000 and includes salary for the Regional Inclusive Emergency Management Planner, admin support, server, printing, and outreach**. Currently, the region does not have a sustainment plan for maintaining the operation of the ReadyHR Registry once Urban Area Security Initiative grant funding ends (August 2014).

Registry Alternatives

Dawn Brantley, the Regional Inclusive Emergency Management Planner, provided some examples of alternate ways to gather larger amounts of more robust data including the U.S. Census Bureau, the Disability Statistics Compendium, and Cornell University's DisabilityStatistics.org. There is **no cost** to access and utilize outside databases such as the Census bureau.

Ms. Brantley also provided a list of additional or alternative programs and efforts to which both she and the Subcommittee could apply their time and effort:

- Development of an EOP Inclusiveness Assessment based on federal requirements, ADA Toolkits, FEMA Guidance, NYC case findings, Red Cross recommendations, and other nationally recognized guidance documents
- Shelter survey assistance
- Building a support network of service and equipment providers for localities to utilize during response & recovery including:
 - Paratransit providers and vehicle owners for evacuation support
 - Lending closets for DME needs
 - Subject matter experts who are willing to provide support in shelters and assist in identifying accessibility solutions
 - Translation/Interpretation services
 - Assistive technology
- Developing a program for distributing disaster public information through service providers and advocacy/support groups directly to their clients or members.
- HRT non-participation policy

Highlights from recent discussions on the ReadyHR Registry:

- Concern during the REMTAC discussion centered on several localities using it operationally and desiring to continue using the data/tool. It was pointed out that any jurisdiction utilizing the data for non-planning purposes is violating the authorization currently in place. Additionally, the registry was never intended to be used for operational purposes and reengineering the registry to support operational use will require extensive time and effort, will likely cause multiple jurisdictions to opt-out, and could potentially create even greater liability for localities (discussed more below).
- Potential problems with changing the purpose of the ReadyHR Registry to an operational tool include:
 - Agreeing on and defining the purpose and clearly communicating that to the public
 - Too many localities opting out of an operational registry
 - HIPAA would still apply to the PDC and to many localities
 - Depending on locality's purpose/use, this may create a program that would be unsupportable. Take for example the goal of identifying addresses to provide transportation during an evacuation. Could your locality provide transportation to 10% of this population (listed above)? If that was your stated purpose for the registry, and you are unable to meet the needs, your city/county could potentially be held liable.
- To increase the number of registrants to make the registry an effective planning or operational tool, localities will need to provide the staff and time to actively conduct outreach. The HRPDC is not staffed to nor was it ever intended for the HRPDC to bear the full burden of registry outreach.
- Some jurisdictions are using the registry to communicate directly with individuals and would like to continue to do so. Jurisdictions will be provided their data before it is purged from the HRPDC servers. It may be considerably more effective to reach out to individuals through their service agencies for a number of reasons:
 - Service provider's databases are maintained regularly by those agencies and organizations instead of emergency managers
 - Eliminates all need to comply with HIPAA and the Virginia Breach Notification law
 - Utilizing service provider databases will reach substantially more individuals (compare the ReadyHR Registry's total of 1,527 registrants to HRT's more than 24,000)
 - Individuals are much more likely to trust and act on information coming to them from a familiar provider or advocacy group
- Two emergency managers expressed concern about discontinuing the registry because it is the only system they have in place to identify or support special needs populations. It should be noted that having a small registry program alone will not be sufficient to show compliance with the Americans with Disabilities Act (ADA), Effort applied to more effective tools and programs will not only do more to comply with the ADA, but will also reach more individuals with disabilities, identify

more needs, and actually provide tangible assistance with planning for an inclusive response and recovery.

Past presentations/information provided

- Presentation to REMTAC on May 28, 2013; http://prezi.com/q5bgrd-z45jb/?utm_campaign=share&utm_medium=copy
- ReadyHR Registry & HIPAA Stakeholder Meeting on October 24, 2013; active link to recording of meeting: <http://readyhamptonroads.org/Practitioners/HIPAA.aspx>
- Presentation to Special Needs Subcommittee Meeting on January 27, 2014;
- http://prezi.com/k79h7iionqr2/?utm_campaign=share&utm_medium=copy
- Presentation to REMTAC January 28, 2014; http://prezi.com/rwoiwjji3pu8/?utm_campaign=share&utm_medium=copy

Comments from the Special Needs Subcommittee:

- The # of registrants for every jurisdiction is statistically invalid to use for planning.
- On a regional level, I do not believe there is a willingness to put in the effort (to make the registry a more effective tool). There are other sources of information in existence to provide the needed information for planning.
- We need to take advantage of existing databases as well as develop relationships with support agencies/networks so planning can tie to response/operations to meet the needs of the target population.
- Based on discussion and experience, it does not seem to be adequate information; statistically valid for planning.
- It seems like going forward effort and resources through other means would be more effective.
- It is time to deal with the operational aspect in conjunction with just planning.
- #s represented on the registry are not statistically relevant for planning. There are many data sources available to provide more effective information for planning.
- Unless the registry contains at least 10% of population, information is insignificant. Might be able to do a registry of service providers, home health, organizations, doctors, pharmacies, etc.
- If the HRPDC needs help [with the Registry], possible volunteers from this committee can help.
- Better use of time and effort to develop alternatives.
- Improving effectiveness would require a significant amount of time, effort, and money.
- I am not sure that in its current format that the registry can be modified to make it more useful because of the limited usage of the registry and the inability to significantly increase the percent of the affected population's participation.

- I think that our effort would be more effective if put into obtaining larger scale data from other sources.
- [To make it more effective] have everyone's local policies listed on site. If possible, create a general working policy for the registry.
- It could be better – it is effective because we have nothing else.
- The PDC [needs] to maintain the registry. The localities cannot perform this task and [discontinuing] would cause us to become non-compliant.
- Gathering statistical data from other sources would at least give each jurisdiction #s to work with which they do not currently have. The only problem with just collecting numbers is that it does not give definitive transportation locations for evacuation purposes.
- Current registry efforts sought micro-data rather than understanding demographics, best practices, resources and complete stakeholder community from a planning perspective. There was no way this approach could provide the information needed. By using specific information from people in need of assistance, it created liabilities and expectations not relevant to its general planning mission.
- The region is desperately in need of a valid planning support capability which can be the "go to" source on special needs planning information, best practices, network development, sme's etc. (as listed by Dawn in this morning's presentation) which supports but does not complete or interfere with locality planning. Over the years this committee has existed, participating in this process has often interfered with local planning which resulted in emergency managers' low participation until more recently. Dawn's focus on critical issues and reorganization has invigorated the process because there is confidence it can be reorganized to be a resource rather than a negative investment. We need planning - based on standard approaches using recognized data sources, then networking and resource identification development, we can enhance operations based on local planning.
- Believe we could be doing much more with the data that has been collected throughout the region for other projects in relation to this initiative.
- Because of the lack of participation in the actual registry by people and families with functional/medical needs...the data is not statistically valid for planning purposes.
- We may do better by working more closely with additional groups that serve the functional/medical needs communities to increase their level of individuals and family preparedness.
- Given HIPAA constraints and the "expectation of service" issues – I don't see any way to improve the tool's effectiveness.
- Work on development of regional 'messaging for S/N populations" and development of a network of direct service providers.

Current Data

Below is a table of the current number of registrants by locality with comparison data for your review.

Locality	Population (2010 Census)	18.4% of population w/disability (from original Medical/Special Needs study)	# of Registrants (as of 2/4/2014)	% of population registered	% of disabled population registered	10% of est disabled population	About how many more registrants would your locality need to make this an effective planning tool?
Chesapeake	222,209	40,886	259	0.12%	0.63%	4,089	3,830
Franklin County	56,159	10,333	2	0.00%	0.02%	1,033	1,031
Gloucester County	36,858	6,782	14	0.04%	0.21%	678	664
Hampton	137,436	25,288	338	0.25%	1.34%	2,529	2,191
Isle of Wight	35,270	6,490	9	0.03%	0.14%	649	640
James City County	67,009	12,330	2	0.00%	0.02%	1,233	1,231
Newport News	180,719	33,252	377	0.21%	1.13%	3,325	2,948
Norfolk	242,803	44,676	221	0.09%	0.49%	4,468	4,247
Portsmouth	95,535	17,578	46	0.05%	0.26%	1,758	1,712
Southampton	18,570	3,417	7	0.04%	0.20%	342	335
Suffolk	84,585	15,564	25	0.03%	0.16%	1,556	1,531
Surry	7,058	1,299	4	0.06%	0.31%	130	126
Virginia Beach	437,994	80,591	173	0.04%	0.21%	8,059	7,886
Williamsburg	14,068	2,589	34	0.24%	1.31%	259	225
York	65,464	12,045	27	0.04%	0.22%	1,205	1,178
Poquoson	12,150	2,236	29	0.24%	1.30%	224	195

Summary

Due to the time, effort, funding, and potential liability for localities and the PDC involved with HIPAA, the Special Needs Subcommittee has reexamined the ReadyHR Registry tool and determined that the registry tool is ineffective as a planning tool, too great a liability, not cost effective, and not the most effective use of time and effort. The Subcommittee recommends applying time, funding, and effort to more effective strategies for compiling planning data and developing operational support tools to assist localities in meeting ADA requirements for an inclusive disaster response and recovery.