

ANI Innovator Profile

International Health Terminology Standards Development Organization (IHTSDO) SNOMED-CT

Interview with Judith J. Warren, PhD, RN, BC, FAAN, FACMI

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www.ihtsdo.org

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The Alliance for Nursing Informatics (ANI) is a collaboration of organizations that represents more than 5,000 nurse informaticists and brings together 30 distinct nursing informatics groups globally.

Mission: To advance NI leadership, practice, education, policy and research through a unified voice of nursing informatics organizations

Vision: Transform health and health care through nursing informatics and innovation

ANI Innovator Profiles Program

The purpose of this program is to capture an ANI Innovator Profile for each ANI member organization to increase awareness and visibility, and to describe their contribution towards a unified voice for nursing informatics.

ANI Innovator Profile – International Health Terminology Standards Development Organization (IHTSDO)

IHTSDO Nursing SIG

The IHTSDO Nursing Special Interest Group is a community of practice for the nursing profession, supporting worldwide nursing participation in the development, validation, uptake, implementation, and correct use of SNOMED CT and related products. We welcome participation from anyone interested in ensuring that SNOMED CT supports nursing requirements for electronic documentation and communication of patient care in any setting - sign up for access to the SIG collaborative space: <https://csfe.aceworkspace.net/sf/sfmain/do/createUser>. Registered observers and members of the SIG will have the opportunity to participate in the process of nominating and recommending the appointment of future SIG Chairs. The Nursing SIG is a member of the Alliance for Nursing Informatics, <http://www.allianceni.org>. On March 17, 2010, the International Council of Nurses (ICN) and the International Health Terminology Standards Development Organisation (IHTSDO) announced a collaborative agreement to advance terminology harmonization and foster interoperability in health information systems.

IHTSDO was established in March, 2007 and acquired the SNOMED CT intellectual property in April, 2007. SNOMED CT is owned, maintained and distributed by the IHTSDO. The IHTSDO is a not-for-profit association which is owned and governed by its national Members. In January 2012 eighteen countries were Members of IHTSDO, more countries are joining every year.

The vision of IHTSDO is to

- Acquire, own and administer the rights to SNOMED CT other health terminologies and/or related standards, and other relevant assets (collectively, the "Terminology Products")
- Develop, maintain, promote and enable the uptake and correct use of its Terminology Products in health systems, services and products around the world
- Undertake any or all activities incidental and conducive to achieving the purpose of the Association for the benefit of the Members.

SNOMED CT contributes to the improvement of patient care by underpinning the development of Electronic Health Records that record clinical information in ways that enable meaning-based retrieval. This provides effective access to information required for decision support and consistent reporting and analysis. Patients benefit from the use of SNOMED CT because it improves the recording of EHR information and facilitates better communication, leading to improvements in the quality of care.

IHTSDO/ SNOMED-CT Interview with Judith Warren:

1. What is the primary mission of IHTSDO/ SNOMED-CT?

The primary mission of IHTSDO is to continue to develop SNOMED-CT and various products such as guidance on implementation and things like that. But for the nursing special interest group, what we see as our reason for being is to support world-wide nursing participation in development, validation, uptake, implementation and the correct use of SNOMED-CT. Correct use is probably the most key, in that we really need to help people learn how to use SNOMED-CT. It is not just a simple vocabulary, it has been developed to work behind the scenes in an EHR and other electronic information systems, so you have to be aware of quite a bit of Informatics and standards & terminology in order to be able to use it correctly. Part of that is it is based on concepts not necessarily words. Because we are an international group we have to be very careful how we translate SNOMED-CT into all the different languages. Right now, there are only two official translations, but we are working on 15 or so others to make sure that between the languages they are all talking about equivalent concepts. We also want to be sure that we have the concepts that will support nursing documentation or the nursing perspective on the patient. We still strongly believe that the terminology is patient centric. But as with every different member of the healthcare team, each team member has a slightly different perspective on the patient so we want to be sure that the nursing perspective is well represented. We work very hard to do that and to accomplish the work. We have one face-to-face meeting a year which rotates around the globe. We also have conference calls. Depending on the work that is going on, they can be monthly or every other month. Those calls are supported by the organization so the only expense to our members to participate is their time. We worked very hard to have a

web presence so we have a worksite where members come in and access our materials and we have various projects plans for people to work on. So that is our commitment and what we do.

2. How many members do you currently have?

Like every organization, we have a membership and we have those precious few volunteers that do the work. The last time we took a look at the number of people who have asked for permission to come into our workspace, which is how we track our membership, we are around 100-120 individuals. Most of the members are from the US or the UK and the other countries are participating with two to five people from each country.

3. What projects is IHTSDO/ SNOMED-CT working on to advance informatics and innovation in healthcare?

One of the projects we finished last year was to review the content for the way that SNOMED-CT addresses occupations in healthcare. And the reason we were concerned was that those concepts about occupations are being used to describe occupations of patients but also occupations of those who consult on patient care. We reviewed everything that affected nursing, there were some errors so we made a report to have the errors fixed and also to add three or four more nursing occupations so those needs could be handled well. That project was very successful.

We also just finished our second annual revision. , We have created a SNOMED-CT encoded nursing problem list and that is now posted at the National Library of Medicine under their Unified Medical Language System. It is free to use for anyone who goes into the [UMLS web site](#). Like SNOMED-CT you have to become a member, but it's free and you can just fill out a form online and then pull down all their materials. It was a US initiated project so we could have a SNOMED-CT encoded problem list to meet Meaningful Use criteria. Many people misunderstand Meaningful Use thinking it's a physician problem list. But if you look at the legislation and all the criteria it is actually a patient problem list. So we wanted to be sure that nurses had one that met all those criteria and was of use. This year we are working on that problem list to make it international in scope and that should be completed within the next year or so. One of the advantages we have at IHTSDO is that we have a partnership agreement with the International Council of Nursing. We are working with them in order to create an international version of a problem list.

As one more example, in the US we had a project that was beginning to look at developing a domain analysis model about the assessment and treatment of pressure ulcers. That was done in conjunction with HL7 and a number of other SDOs. They needed to have terminology to populate that model, so we partnered with that group and made sure SNOMED-CT had all the terminology that they needed to make that model work.

4. What value do you see in IHTSDO/ SNOMED-CT being an ANI member?

As we applied for membership to ANI, we had a long talk about it since we applied just before we became an international organization. We saw this membership very much as an organization of nurses in the US wanting to be part of the informatics initiative. At that time all

of our membership was working primarily with the implementation of EHRs. So we were trying to find people to collaborate with that we could share lessons learned, etc. and we appreciated the part of ANI working on various responses to US initiatives. As we progressed and we became an international membership, we still see ANI as a place to debate some of the issues. What is interesting to note is that many of the countries that are represented in our organization have some of the same healthcare issue that ANI addresses on their responses. So what we are seeing in our other country members is that people are going to the ANI web site and looking at some of the comments and letters that ANI has written and other materials there. While the other countries do not see that it speaks for them in the capacity that ANI does in the US, what they do see is the clarity of laying out the problems or issues so they can view that perspective and adapt what they want into their own countries. That has been an enormous asset for us, to bring all these perspectives together. In our meeting what has made most of us proud to be part of the process is that nursing at an international level has a lot of shared beliefs, shared vision and shared practice. So we are always coming together and finding out how much we are alike and then using our differences to enrich our own practices. From ANI, we get a broader forum and other perspectives of how people view health issues.

5. In what way(s) is IHTSDO/ SNOMED-CT supporting ANI Initiatives e.g. the [ANI Consumer Pledge](#), ANI Comments & Testimony, the Emerging Leader Program, etc?

I am not sure we have participated in the ANI Consumer Pledge since most of our members see that as a US centric activity, but some have discussed taking it back to their own countries and starting something there.

We encourage our individual members who are interested to provide some input into the comments and testimony and we have had some success in doing that. About one-third of our membership comes from the US and most of them are in leadership positions themselves, so they are very interested in the ANI comments and testimony initiative.

6. What is IHTSDO/ SNOMED-CT's vision for the future of nursing informatics?

We are deeply committed to the role that terminology plays in capturing and revealing patient information especially in electronic format. We are heavily into the electronic space with working on SNOMED-CT. What we see in the future is really paying attention much more to the nursing knowledge and information that is needed in order to support nurses at the bedside and caring for their patients. We work with our colleagues within our group and some of the other special interest groups in IHTSDO to understand clinical decision support more, and to understand other initiatives such as querying for data, making sure that the SNOMED-CT product supports all of that in a good way. We are also beginning to take a look at the knowledge piece, which is why we became very active with the pressure ulcer project. It brought together for us the fact that we really need to tighten up the feedback loop between research being done about what works best and then working with people who pull the evidence out and write up guidelines for care. Again, working with the people who make those guidelines actionable, which means doing domain modeling and adding terminology to those models so they can be built out on the EHR applications. We are also going to find out we are just beginning to understand this whole process. That it is going to be harder, more challenging

and at the same time easier and more rewarding than we think of today. But, I think we are going to find that the nurse informaticist role is one that is only going to grow more in importance in developing these knowledge tools to enhance nursing care of our patients.

7. Additional Comments

There is plenty of work to do, even if you don't like the notion of developing a terminology. Through the examples I've given there is the ability to really look at what does it mean to represent knowledge within an EHR; what are the components for that; and, what do we need to look at the quality of our care? It's also a good place if you want to start looking at what's happening internationally. We have a good set of members that really enjoy working with each other. For those of us in the US, the IHTSDO unofficial language is English so we are not challenged by having to think in another language, so we would welcome people to join us on our conference calls. To find out when those are and how to dial in you just go to our web site and sign up for a user name and password and then you are able to participate at all levels.

Biography for Judith J. Warren

Judith J. Warren, PhD, RN, BC, FAAN, FACMI is the Christine A. Hartley Centennial Professor of Nursing and Assistant Director of the Frontiers Heartland Institute of Clinical and Translational Research's Center for Biomedical Informatics. She developed, in partnership with Cerner Corporation, the Simulated E-health Delivery System (SEEDS), adapting electronic health record software, to teach students how to analyze data from virtual patient case studies, simulations, and clinical experiences while developing informatics competencies. This program is now used in over 50 school of nursing. She is a member of the National Committee on Vital and Health Statistics (NCVHS), co-chair of its Standards Subcommittee, and member of the Executive Subcommittee and Quality Subcommittee. NCVHS is an advisory body to the Secretary of the U.S. Department on Health and Human Services on health data, statistics and national health information policy. She is a member of the National Quality Forum's (NQF) Health Information Technology Advisory Committee and consults with NDNQI on moving their nursing quality indicators to the new format of eMeasures required by NQF for endorsement. Dr. Warren is the past co-chair of HL7's Patient Care Technical Committee, an informatics standards development organization. She serves on the Quality Committee and the Nursing Special Interest Group of the International Health Terminology Standards Development Organization (IHTSDO) which develops SNOMED CT (a leading multidisciplinary standardized terminology). She is a member of the Quality and Safety Education for Nurses (QSEN) faculty and a consultant to Technology and Informatics Guiding Educational Reform (TIGER). Dr. Warren is a Fellow in both the American Academy of Nursing and the American College of Medical Informatics. She has taught, published, and conducted research in nursing informatics since 1988. She is an ANCC certified Informatics Nurse.

Recorded: September 26, 2012

For full interview recording you can [click here](#) or visit <http://www.allianceni.org/members.asp>