FACING THE WORLD WIDE HEALTH CRISIS WITH VOCABULARY CONTROL AND STANDARDS: NKOS WORKSHOP 2020

STANDARDS – THE BEDROCK OF OUR CONNECTED WORLD

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AGENDA

• Personal Info/Background
• Standards and their place in the world
• Why do they matter now?
BACKGROUND INFO

- VP of Content Management at ITHAKA, which is a not-for-profit dedicated to improving access to knowledge around the world and making it more effective and affordable
- Products
  - JSTOR – an online archive of academic journals, books, and research reports
  - Portico – a preservation service for born-digital content for publishers and libraries
  - ITHAKA S&R – Strategies and research supporting higher education
- Before ITHAKA, nearly 20 years in health sciences publishing, including Elsevier and Wolters Kluwer
- FULL DISCLOSURE – NISO Board Member (currently Treasurer) since 2016
STANDARDS AND THEIR PLACE IN THE WORLD

• Whether we know it or not, standards help us every day – some in ways we see, and others in ways we don’t

• In exchange of information…
  • TCP/IP enables communication
  • DTD/schemas enable information architecture
  • Z39.50 enables information retrieval
  • Z39.19 enables categorization (controlled vocabularies)

• Imagine a world without these standards (Nevermind: it’s too scary!)
WHAT WE’RE TRYING TO AVOID 😊

ALL MODERN DIGITAL INFRASTRUCTURE

A PROJECT SOME RANDOM PERSON IN NEBRASKA HAS BEEN THANKLESSLY MAINTAINING SINCE 2003

Source: xkcd.com
“ALL MEDICINE IS LOCAL”

• Judy and Travis are charged with putting solid, peer-reviewed information into the hands of health care professionals – from a policy perspective and from a clinical guidelines perspective
• The amount of disinformation available on the web is astounding
• In health care, being right can be a matter of life and death
• Doing this without standards that validate that the information is from a trusted source would be malpractice
• Standards enable them to do their jobs
• This is always important. It is even more important in 2020, when a global pandemic has raised the stakes
DIFFERENT USERS, DIFFERENT NEEDS

Consider the needs of the following health-care professionals:

- A nurse practitioner at a local health clinic
- A pediatrician in private practice
- An EMT responding to a health emergency at a local shopping mall
- A registered nurse in a critical care unit at a large hospital
- A medical coder processing insurance forms

All have different needs, at different times, and with different points of entry into the current accepted practice of health care.
• Without standards, and without the peace of mind that standards can bring to information architecture, satisfying the needs of these varying users would be impossible.

• I can Google “what to do if my left arm is numb,” but the only benefit you’ll get is targeted Google ad words that will follow you for weeks.

• Managing health care information is difficult in normal times, but particularly important in times like this, when knowledge of COVID-19 is evolving daily.
  • Having standards increases the likelihood that “trusted sources” can be validated.

BRINGING ORDER OUT OF CHAOS
STANDARDS THAT HELP NORMALIZE THE WORLD (NOT A COMPLETE LIST!)

- ISO/ANSI/NISO/W3C/NKOS
- ORCID/ISNI for contributor names
- XML, HTML, PDF, and ePUB for formats
- Industry/National Groups
  - Library of Congress (LCSH)
  - BISG (ONIX metadata for books)
  - STM
STANDARDS ENABLE

• Validity of source (Is information credible?, Can I trust it?)
• Quicker/easier exchange of information
• Seamless updating of information (is this the latest knowledge?)
• Discoverability – standards around taxonomies/NKOS are critical, because of the disambiguation they can provide for search
WHAT DO YOU CALL YOUR ANNUAL VISIT TO THE DOCTOR?

• Physical
• Checkup
• Check-up
• Health check
• Physical check-up
• Physical exam
• Physical examination

• Health examination
• Doctor’s visit
• Looking over
• Yearly checkup
• Medical examination
• Once over
IN A GLOBAL, CONNECTED WORLD…

- That might seem trivial, but multiply the number of terms by different ”lenses” in the world, and it becomes significant.
- Or think about the variability in ASCO’s world of Oncology, which is just ONE discipline of medicine, and medicine is just one branch of health sciences.
FINAL THOUGHTS

• The world would still spin without standards
• But access to information in a timely, verifiable way would be severely limited
• As tough as 2020 has been, hard to think about how much worse it would be without the information made available by standards
THANK YOU

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