2017 ANNUAL REPORT
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About Regenstrief Institute

Regenstrief Institute, Inc. is non-profit 501(c)3 research organization driven by a mission to connect and innovate for better health. Regenstrief serves as the overall steward and standards development organization (SDO) for LOINC.

The LOINC team within Regenstrief maintains the LOINC database and supporting documentation, processes submissions and edits to the content, develops and curates accessory content (descriptions, hierarchies, other attributes, etc.), develops the RELMA mapping program, and coordinates LOINC releases. The team also cultivates the LOINC community and the standard’s adoption worldwide.
Letter from the Director

It is my great pleasure to share with you LOINC’s inaugural Annual Report. Back at the start in 1994, the early LOINC participants had a vision of creating universal standard that would enable health data to be transmitted and understood by different computer systems. They also knew that creating the standard was only part of the story; the more it was used, the greater its value and the better it would become.

As this report shows, we can now see LOINC’s positive effects on health around the world. Clinical systems in many countries are processing data coded with LOINC for hundreds of millions of patients. It’s quite remarkable just how ubiquitous LOINC has become.

Inside this report, we share our current approach to developing LOINC and give a high level view what’s happening in the vibrant LOINC user community. The year 2017 contained many significant advancements in the LOINC standard and associated tools, and we review a few main highlights, including a brand new loinc.org website, new release artifacts, and of course significant content additions. We are grateful to the volunteers of the LOINC Committee, who continue to advise and set key policies, as well as the many users who submit term requests, produce language translations, and contribute in other ways.

Over the course of the year, we worked closely with many wonderful collaborators. We were especially excited to launch a comprehensive collection of radiology procedure codes, the LOINC/RSNA Radiology Playbook and to see the significant accomplishment of a new specification called LIVD for in vitro diagnostic test vendors to publish linkages from the test’s internal codes to LOINC.

Looking ahead to 2018, we see many exciting opportunities. Based on requests from the user community, we’ll be expanding LOINC’s coverage in core areas as well as emerging domains like genetic reporting, social and behavioral determinants of health, and environmental exposures. We are also eager (fingers crossed) to make the LOINC release content available via a FHIR-based terminology services API.

We are continually inspired by how people are using LOINC. If you get a moment, we’d love to hear your story of success with LOINC. Just drop us a note at https://loinc.org/contact/.

Thanks for making this work so interesting and enjoyable.

Happy LOINCing!

Daniel Vreeman, PT, DPT, MS
Director, LOINC and Health Data Standards
Regenstrief Institute, Inc.
We imagine a world where people experience optimal health catalyzed by a seamless network of health information systems.

LOINC is a freely available global standard, delivered with a rich set of implementation tools, used by a diverse global community, who propel its continuous development.

Today, LOINC contains concepts for everything from a serum alpha 1 antitrypsin level to a zygomatic arch x-ray report. For each concept, LOINC contains many other rich details, such as synonyms, units of measure, and carefully crafted descriptions.
Strategy

Our mission is to develop and advance the adoption of data standards that enable efficient transmission, understanding, and use of health data. We want to see LOINC integrated into every clinical information system that shares or aggregates data. To accomplish this, we are committed to:

- Developing rich content in LOINC that supports today’s health systems
- Developing tools that help the community implement LOINC
- Educating individuals and organizations on the benefits of and best practices for implementing health data standards, including LOINC

At LOINC, our guiding principle is “We Learn.” We seek to iteratively improve how we develop and deliver data standards with the end goal of making health data more portable and understandable to different computer systems.

We take an open approach, striving to understand community needs, seek feedback continually, and keep barriers to participation low. We investigate matters thoroughly and make decisions based on expert knowledge and best-available data. At the same time, we focus on practical solutions, not letting “theoretically perfect” prevent our work from being efficient and useful.

With this strategy in 2017, we launched an exciting set of new initiatives, reimagined some existing staples, and continued to grow in both breadth and depth. We’re excited about the promise that 2018 holds.
LOINC use has grown substantially in the past 20 years. The year 2017 ended with 57,015 LOINC users representing 170 countries—a 20% rise in the number of registered accounts over the previous year. This growth includes the removal of over 4,000 duplicate and invalid accounts in February 2017.

LOINC is now used in nearly every corner of the planet.
Since its inception, Regenstrief has developed LOINC as an open standard. We welcome requests for new terms, and it’s because of submissions from the LOINC community that we’ve been able to grow and adapt so quickly. In 2017, we received new term submissions from organizations in 14 countries.

Any LOINC user can submit a new term request, either by RELMA or via a spreadsheet template. The details of what information we need (which varies by domain) are described on the LOINC website at: [loinc.org/submissions/new-terms/](http://loinc.org/submissions/new-terms/)

Each term request undergoes rigorous review. The LOINC content development team follows a thorough quality review process before adding new content. Complex and systematic naming issues are reviewed by the LOINC Committee. After passing our quality review process, they are made available back to the submitter and published for public viewing at: [loinc.org/prerelease/](http://loinc.org/prerelease/)

All term requests completed within a release cycle are packaged up into the next official new LOINC version, which are published twice yearly.

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<tr>
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<tbody>
<tr>
<td>Submissions</td>
<td>265</td>
</tr>
<tr>
<td>Submitters</td>
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</tr>
<tr>
<td>Clinical terms submitted</td>
<td>2,006</td>
</tr>
<tr>
<td>Laboratory terms submitted</td>
<td>2,755</td>
</tr>
</tbody>
</table>

Submitters to LOINC

LOINC grows because you ask!

Learn how to submit your term for inclusion in the LOINC database:

[loinc.org/submissions](http://loinc.org/submissions)
Community engagement

LOINC users form a vibrant community with a wealth of diverse expertise, resources, and knowledge. Regenstrief continues to foster community participation in key ways.

LOINC MAILING LIST

The LOINC mailing list our main channel for spreading key LOINC news. We recommend that all LOINC users subscribe. We are mindful of not overwhelming your inbox, but this is where we will send important announcements (like when a new release is available!) and other key updates from LOINC-land.

<table>
<thead>
<tr>
<th>List subscribers</th>
<th>18,194</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change over previous year</td>
<td>+290 %</td>
</tr>
</tbody>
</table>

LOINC FORUM

The online LOINC forum facilitates conversations between LOINCers. LOINC community members are often best poised to help each other with questions about implementation and a variety of other topics. We recommend subscribing to the forum digest to receive an email with new postings.

<table>
<thead>
<tr>
<th>Conversations</th>
<th>714</th>
</tr>
</thead>
<tbody>
<tr>
<td>Customers</td>
<td>487</td>
</tr>
<tr>
<td>Messages received</td>
<td>1,090</td>
</tr>
</tbody>
</table>

LOINC USER INQUIRIES

The LOINC team at Regenstrief provides limited technical assistance to its Premium Members. We do also welcome feedback from the broader LOINC community. The best ways to alert us to an issue or ask a question is via the Contact Us form on the website. Using this form ensures that your question gets routed to the right team member. Such inquiries are managed with help desk software to help us stay coordinated.
Community outreach

LOINC CONFERENCE

In December, we hosted our inaugural and highly successful LOINC Conference. The conference offered an expanded set of training sessions that gave attendees the ability to customize the schedule to fit their unique needs. The conference also featured a poster reception with a chance to network with fellow LOINCers, and culminated with the public Laboratory LOINC Committee Meeting.

LOINCinars

Throughout 2017, the team hosted a series of webinars for our Premium Members. These sessions covered a variety of topics included an inside look at LOINC submission processes, a sneak peek of the new LOINC Groups file, and deep dives on LOINC artifacts.

LOINC team members were also spotted presenting at national and international events throughout the year.

Highlights included:

- APTA Combined Sessions Meeting in February
- LTPAC Summit in June
- HealthInsights in July
- MedInfo in August
- Multiple presentations at AMIA in November
- FHIR dev days in November
- RSNA Annual Meeting in November
Susan Matney, PhD of Salt Lake City, Utah was presented with the 2017 award at the annual LOINC meeting in June. Matney is long-time active member of the LOINC community.

Matney, a veteran nurse, is now a Senior Medical Informaticist with Intermountain Healthcare. She is a Fellow of the American Academy of Nursing and was selected as the 2007 pioneer in nursing informatics by the AMIA nursing working group. Recognizing the need to harmonize the use of LOINC with another leading multidisciplinary terminology, Dr. Matney led efforts to create collaboration between the two to meet the needs of the nursing community.

As part of the Nursing Knowledge Big Data Science Intitative, Dr. Matney co-leads a workgroup focused on clinical models and terminology standards. Matney was instrumental in supporting the updating, coding, and inclusion of the Nursing Management Minimum Data Set (NMMDS) in LOINC.
LOINC Database

In 2017, the LOINC database grew by 3,151 new terms. Highlights of the new content include:

- New laboratory panels for colorectal and breast cancers, Neisseria meningitidis serogroup DNA, kidney failure, Dengue and Zika viruses, and several veterinary toxicology panels
- Multiple post-acute care panels for the Centers for Medicare and Medicaid Services
- Renal therapy and education goal panels for the National Institute of Diabetes and Digestive and Kidney Diseases
- Updated HEDIS value sets
- 150 new Document Ontology terms
- 50 new terms for CDC case reporting of clinical history concepts

LOINC content was also significantly improved in 2017 by edits to 11,279 terms. Based on recommendations from one of the Committee’s Special Topics Workgroups, we updated the naming conventions for terms with PCR-based methods. Additionally, as part of a large initiative with the Radiological Society of North America (RSNA), edits were made to nearly 5,000 radiology terms to conform to the new LOINC/RSNA Radiology Playbook model.

Regenstrief also published several new release artifacts in 2017. We are excited about publishing the alpha version of LOINC Groups, a flexible, extensible, and computable mechanism for rolling up groups of LOINC codes. LOINC Groups offer significant benefit for aggregation of LOINC codes for display on flowsheets, in clinical decision support algorithms, in quality measurements, and many other purposes. In addition, Regenstrief published new release artifacts for LOINC Parts and LOINC Answers associated with all LOINC terms and significantly enhanced the LOINC Multiaxial Hierarchy to include all LOINC terms.
The December release of RELMA included functionality to support the filtering of search results by a user-defined subset rather than search the 80,000+ LOINC terms. This is especially useful for members of the LOINC community who live in countries with a nationally curated list of approved codes. The subset toggle functionality at the bottom of the screen provides an easy way to turn the filter on and off as needed.

Other highlights from the year:

- Enhanced HIPAA Attachments screen to include visual highlighted of preferred document for payers to utilizing when requesting additional information.
- Common Tests search restriction now includes a “Clinical Terms Only” option.
In late Spring of 2017 we enhanced the popular search.loinc.org application with a user profile login that allows users to save preferences (such as a preferred language).

We also enhanced search.loinc.org with a thorough documentation of its advanced search syntax and capabilities. The power of these tools for narrowing in on the most appropriate LOINC term wasn’t apparent to many users. But now, complete descriptions and examples are available right within the application.

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<tbody>
<tr>
<td>Sessions</td>
<td>150,941</td>
</tr>
<tr>
<td>Users</td>
<td>43,180</td>
</tr>
<tr>
<td>Pageviews</td>
<td>1,229,268</td>
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</table>

1,157,764
Total queries made on the search.loinc.org website in 2017

loinc.org/search
New LOINC.org

The LOINC.org website was relaunched in the first quarter of 2017. Not merely a facelift, the site also offers many features and improvements over the previous iteration. New capabilities were also added throughout the year.

- Faster loading and mobile responsive
- Cohesive design with intuitive navigation
- Reorganized structure
- New domain-specific content areas such as HIPAA Attachments and Social Determinants of Health
- Duplicate user accounts were removed
- LOINC Groups community submissions (More on page 17)
- Targeted Subsets for use within RELMA (More at loinc.org/subsets)
To help guide LOINC development, Regenstrief has organized the LOINC Committee. Comprised of volunteers from academia, industry, and government, the LOINC Committee serves as the main advisory body for LOINC. The LOINC Committee serves a number of key roles in LOINC development including important decisions related to naming conventions and setting policies for the development process. The Committee has two primary divisions:

- **Laboratory LOINC Committee** which deals with observations made on specimens;
- **Clinical LOINC Committee** which deals with observations made on patients.

All of the agendas and meeting handouts for Committee meetings are publicly available on the LOINC website. This year, the LOINC Committee discussed and made recommendations about many key topics, including:

- New release artifacts (LOINC Groups, LOINC Part File, and LOINC Answer File)
- New versioning system for LOINC releases
- Creation of a revised DisplayName for LOINC terms

In 2017, the LOINC Committee also ratified a new set of governance principles for how it operates. The new principles add additional structure around Committee membership as well as specific categories of membership (Individual, Organization, SDO, International Affiliate, etc). These changes are now in effect. Members of the LOINC community interested in joining the committee can visit the website for more details and to apply.

loinc.org/committee
In June 2017, the IVD Industry Connectivity Consortium (IICC) announced the availability of a new specification for digitally publishing connections between vendor IVD test results and LOINC terms. The new specification, LIVD, is a major advance for interoperability of laboratory data. The LIVD specification was a collaborative effort between the IICC, IHE Pathology and Laboratory Medicine, Regenstrief Institute, the U.S. Centers for Disease Control and Prevention, and the U.S. Food and Drug Administration.

The enhanced vendor test format contains key data elements for linking IVD test results to LOINC terms, including the manufacturer, the instrument model, an instrument universal identifier (UDI), the vendor transmission code, vendor specimen description, vendor result description, the test name, as well as optional data elements (e.g., a reference ID to the package insert, additional instructions or comments related to the test). The specification can be used to publish these linkages in a human readable spreadsheet, and a computable format using JSON (JavaScript Object Notation). The HL7 Orders and Observations Workgroup has also launched an effort to create a FHIR-based representation of LIVD content.

Download the LIVD specification and samples from: loinc.org/livd

In 2017, the United States Food and Drug Administration (FDA) formed a LOINC Working Group to make recommendations regarding the mandate to submit LOINC codes to regulators. This Working Group was a collaborative effort among the FDA, National Cancer Institute, National Library of Medicine, Regenstrief Institute, and CDISC. In November 2017, the FDA made available a final version of the Working Group’s recommendations. The Working Group recommendations are intended for consideration by FDA as they contemplate future LOINC requirements.

As described in the recommendations document, CDISC-compliant submissions currently support the inclusion and submission of LOINC codes as part of the laboratory (LB) domain. LOINC users are encouraged to review the recommendations from the Working Group and continue following FDA guidance that is published as updates to the Study Data Technical Conformance Guide (TCG).

The effective date for the LOINC mandate is March 2020. You can find additional details on the LOINC website: loinc.org/regulatory
Special initiatives

FINALIZATION OF THE LOINC/RADLEX PLAYBOOK

September 2017 was the culmination of a multi-year effort to develop a unified model for naming radiology procedures. We are pleased to announce complete transformation of LOINC’s radiology content into the LOINC/RSNA Radiology Playbook that is now available with each LOINC release. The LOINC/RSNA Radiology Playbook provides a universal terminology standard for radiology orders and results.

Funded by the NIH and Department of Defense, the LOINC team collaborated with the Radiological Society of North American (RSNA). The two teams designed and implemented a new model that combined the best of LOINC and RadLex’s existing approaches. The collaboration had six primary aims:

1. Develop a unified model for radiology procedure names
2. Transform existing LOINC procedure codes into the new model
3. Create a mapping between all attribute values in LOINC to their equivalent concepts in RadLex
4. Create a mapping between existing procedure codes in the RadLex Core Playbook and the corresponding codes in LOINC
5. Develop a single governance process for managing the unified terminology
6. Publicly distribute the terminology artifacts

Together, Regenstrief and the RSNA will continue to develop the LOINC/RSNA Radiology Playbook under the guidance of a new committee forming in 2018. New radiology procedures will be added only to LOINC (not to the sunsetting RadLex Playbook), but will be linked through the new model to attribute values in LOINC (LOINC Parts) and RadLex (RIDs).

loinc.org/playbook

GUIDE FOR USING LOINC MICROBIOLOGY TERMS

In August 2017, the LOINC team began work to create a new kind of reference document for the LOINC community—a Guide for Using LOINC Microbiology Terms. This work, funded by the U.S. Food and Drug Administration, aims to provide definitive guidance and a decision making framework for linking the test result output from infectious disease IVD tests to the appropriate LOINC terms.

The guide is being developed through an iterative process with much stakeholder feedback. The first draft was shared with the LOINC Community at the Winter 2017 Conference. After pilot testing in early 2018, the guide will be submitted for final approval to the Laboratory LOINC Committee in June 2018 and published publicly thereafter.

loinc.org/groups

LOINC GROUPS

With funding from National Center for Advancing Translational Sciences, the LOINC team set out to create a computable way to roll-up LOINC codes. A LOINC Group is sets of terms that might be considered equivalent for a particular purpose like display, retrieval, or research. Beginning with the June 2017 LOINC release, we are now publishing the LOINC Group File. This journey is still early; however the Alpha version is available for download.

We also created a portal for users to share their own groups of LOINC terms that they treat as equivalent for a particular purpose. With a little metadata and a list of LOINC codes, you can contribute a valuable resource to others and recommend inclusion in the official LOINC Group file. Visit the website for more details.
Help support a noble cause

The goal of LOINC is to help people experience optimal health through seamless information processing. This goal is attainable, but only with your support. We’d love for you to work with us to create this reality. As an individual, you can make a one-time contribution to Regenstrief Institute. Alternatively, we offer several sponsorship opportunities for organizations.

loinc.org/donate

LOINC Premium Members

Show your individual support for LOINC and get some special benefits in the process. Starting at $75 for one year, you can take advantage of these perks to take your LOINCing to the next level. You can also get a Mapping Validity Checker for an additional fee. See the following website location for complete details as well as our sponsorship program.

loinc.org/members

» Premium support
» Change file notice with each release
» 10% Off LOINC Conference admission
» 20% off LOINC Essentials eBook
» Archive of past LOINC releases
» LOINCinar videos
» Mapping Validity Checker