



The COVID-19 & Cancer Consortium

Session 3: Lessons learned from the COVID-19 & Cancer Consortium (CCC19)

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*Enabling 21st Century Applications for Cancer Surveillance through
Enhanced Registries and Beyond*

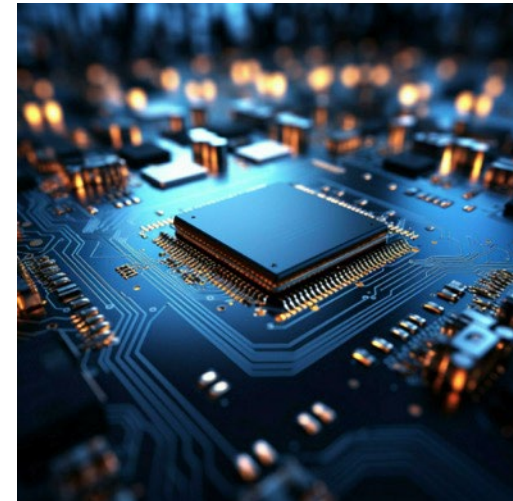
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ccc19.org

NCT04354701

Informatics = People + Process + Technology



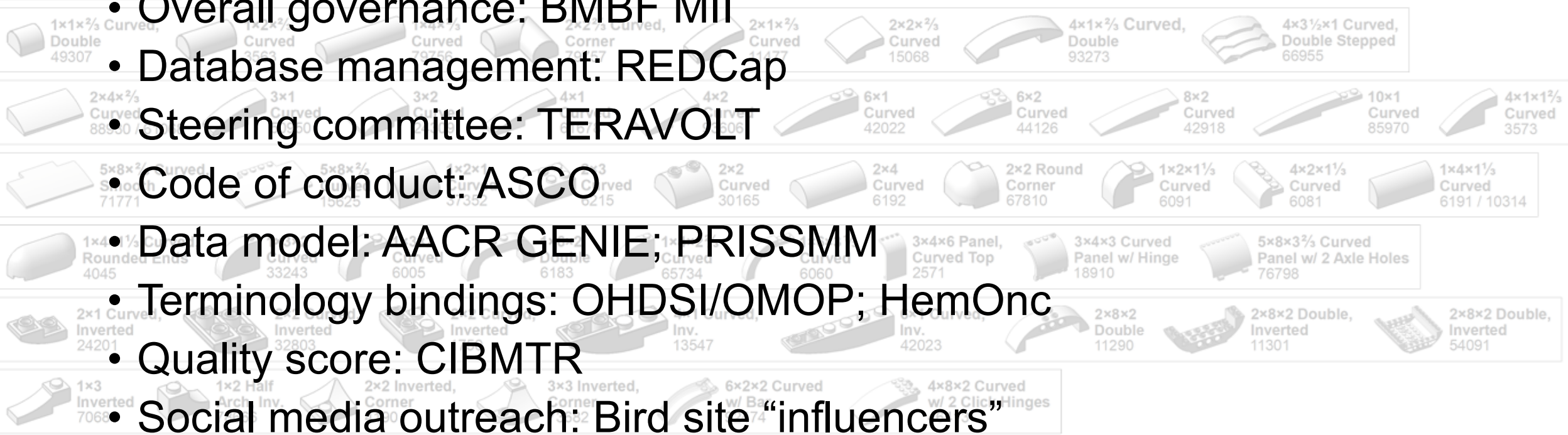


CURVED-cone



The pieces were there – putting them together was the hard part.

CURVED-curved



- Overall governance: BMBF MII
- Database management: REDCap
- Steering committee: TERA VOLT
- Code of conduct: ASCO
- Data model: AACR GENIE; PRISMM
- Terminology bindings: OHDSI/OMOP; HemOnc
- Quality score: CIBMTR
- Social media outreach: Bird site “influencers”

CURVED-arch



- Analytics: Formal and informal¹ teachings of Frank Harrell
- Patient engagement: Open Notes; Count Me In

¹<https://hbiostat.org/blog/>



Critical elements needed to populate a registry such as CCC19 were **not to be found** in EMR structured data (sEMR).

Often to be found in the sEMR

Usually **NOT** found in the sEMR

Date of birth

Biologic sex

Race/Ethnicity¹

Medications as prescribed

Laboratory test values

Procedures

Mortality

Hospitalizations

Place and circumstances of birth

Gender orientation and sexual identity

Other social determinants of health

Medications as taken; **Regimens**

Radiology and pathology images

Toxicity and burden of treatment

Cancer status

Performance status



More than 600 investigators

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Key takeaways from CCC19 Y1-Y4

- **Goodwill** is critical but can be fleeting; **rewards** are needed to sustain enthusiasm.
- **Elusive elements** (e.g., cancer status^{1,2}, ECOG performance status^{1,2}, institutional factors³, vaccination⁴) drive outcomes.
- Allowing **unknown values** and tolerating **missingness** is important, as long as there is a means for accountability.⁵
- Measuring **impact** is much more difficult than collecting data.

¹Kuderer et al. 2020 *Lancet* [https://doi.org/10.1016/s0140-6736\(20\)31187-9](https://doi.org/10.1016/s0140-6736(20)31187-9)

²Grivas et al. 2021 *Ann Oncol* <https://doi.org/10.1016/j.annonc.2021.02.024>

³Hawley et al. 2022 *JAMA Netw Open* <https://doi.org/10.1001/jamanetworkopen.2021.42046>

⁴Scmidt et al. 2022 *Ann Oncol* <https://doi.org/10.1016/j.annonc.2021.12.006>

⁵CCC19 2020 *Cancer Cell* <https://doi.org/10.1016/j.ccell.2020.10.022>



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