The Radiation Oncology Data Sharing Landscape … Registries, Clinical Trials, Data Warehouses

Colleen Fox, PhD, DABR – Data Sharing Basics
Sarah Quirk, PhD, MCCPM – Clinical trial data sharing
Scott Hadley, PhD – Data sharing standards, IHE-RO
Data Reporting Needs and Cancer Registries
The data sharing landscape

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Disclosures

• I have not received funding related to the topics discussed in this talk.

• My first hand experience is primarily limited to Varian and Epic. As a result most examples will be in software from these vendors. This talk is not an endorsement of any of the mentioned tools or applications.
Objectives

1. **Think** about who should be using radiation oncology data and what data they need.

2. **Question** if the dissemination of this data is accurate and efficient.

3. **Get involved** and make improvements (inside and outside Radiation Oncology)
DATA!
Naming / Ontology
Consistent use of data elements
Database Structure
GUI Human Factors

Workflow

Quality Assurance
Efficiency
Why Share Data

1. High quality patient care

2. Funding

3. Advancement of the field

- Coordination of care
- Previous treatments
- Accreditation
- Technique assessment / standards development
- Quality improvement / incident learning
- Equipment and staffing decisions
- Quality reporting programs
- Billing
- Cancer registries
- Research
## Minimum Data Elements

### Treatment Course Data Elements
- Diagnosis
- Modality
- Technique
- # of fractions planned
- # of fractions delivered
- Start date of treatment
- End date of treatment

### Prescribed Dose-level Elements
- Anatomic site
- Total dose planned
- Total dose delivered

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Basic Data Sharing

Who needs Rad. Onc. Data?

- Coordination of care – Providers outside Radiation Oncology
- Cancer registries – Local registrars
- Previous treatments – Providers at another institution
- Billing
- Quality improvement / incident learning
- Quality reporting programs
- Equipment and staffing decisions
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- Accreditation
- Research
**Synoptic Radiation Treatment Summary**

<table>
<thead>
<tr>
<th>Radiation course summary</th>
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<tbody>
<tr>
<td>Treatment indication</td>
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<td>Concurrent systemic treatment?</td>
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<td>RT course discontinued early?</td>
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<td>Patient experience</td>
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<td>Follow-up plan</td>
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<td>Dose per Fx (cGy)</td>
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Abbreviation: RT = radiation therapy.

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How to Share the Treatment Summary

1. Store in radiation oncology system as a document, possibly hand copy to hospital EMR
   • Not visible to all, manual copies and data entry are error prone

2. Share the document through a document interface
   • Visible but does not result in discrete data elements in the hospital EMR

3. Share the data elements with the hospital EMR with a software data link
   • Discrete data, but error prone and limited. Vendors are working with IHE-RO to improve this

4. Set up a data warehouse that uses scripted queries to combine minimum data elements from the various hospital EMRs and other databases.
   • Highly flexible but needs resources to develop and maintain.

Cancer Registries

• Monitor cancer trends over time.
• Show cancer patterns in various populations and identify high-risk groups.
• Guide planning and evaluation of cancer control programs.
• Help set priorities for allocating health resources.
• Advance clinical, epidemiologic, and health services research.
• Death data
• Software for data collection and review

https://www.cdc.gov/cancer/npcr/about.htm
Cancer Registries

• National Program of Cancer Registries (NPCR)
  • Established by the U.S. Congress in 1992, administered by the CDC
  • Collect data on cancer occurrence, type of initial treatment and outcomes
  • NPCR funds registries in 46 states, the District of Columbia, and 3 territories
  • [https://www.cdc.gov/cancer/npcr/index.htm](https://www.cdc.gov/cancer/npcr/index.htm)

• National Cancer Institute’s (NCI’s) Surveillance, Epidemiology, and End Results (SEER) Program
  • 12 U.S. states, 4 metropolitan areas, plus Native American populations
  • [https://seer.cancer.gov/](https://seer.cancer.gov/)

• National Cancer Database (NCDB)
  • Jointly sponsored by the American College of Surgeons and the American Cancer Society
  • Clinical oncology database sourced from hospital registry data that are collected in more than 1,500 Commission on Cancer (CoC)-accredited facilities.
  • [https://www.facs.org/quality-programs/cancer/ncdb](https://www.facs.org/quality-programs/cancer/ncdb)

• Canadian Cancer Registry (CCR)
  • 13 Canadian provincial and territorial cancer registries collaborating with Statistics Canada
  • [https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=1215604](https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=1215604)
Treatment Course / Volume Elements
• Date Radiation Started
• Location of Radiation Treatment (1 facility or multiple)
• Number of phases of radiation to this treatment volume
• Radiation treatment discontinued early
• Total dose (delivered, Sum from all phases in course)
• Radiation / Surgery sequence
• Date Radiation Ended

Phase Elements (*a phase ~ a plan)
• Primary Treatment Volume
  • primary anatomic target, coded list
• Radiation to Draining Lymph Nodes
• Modality
  • Examples: 02 External beam, photons; 04 External beam, electrons; 08 Brachytherapy, Interstitial, HDR
• Technique
  • Examples: Low energy x-ray / photon, 2-D, Conformal or 3-D, Intensity Modulated, SBRT / SRS [NOS, robotic, or Gamma Knife], CT-guided online adaptive, MR-guided online adaptive
• Dose per fraction (cGy)
• Number of fractions (delivered)
• Total dose (delivered)
Cancer Registry Registrars

Comb for data in various hospital databases and treatment summary notes.

Often must interpret free text notes – error prone

Would benefit from a standard treatment summary.

Would benefit more from a curated data warehouse.
Minimum Data Elements, CoC Treatment Summary follow Cancer Registry:

• Anatomic site of each prescribed dose level
• Primary anatomic site(s) targets for each dose level
• Nonoverlapping

• MDE recommends using the names in STORE phase1 Radiation Primary Treatment Volume table.

• The CoC Treatment Summary stresses not to use ‘PTV’ but does use normal structure nomenclature from AAPM Task group 263.

What do you use?
<table>
<thead>
<tr>
<th>Key</th>
<th>Value</th>
<th>Site</th>
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<th>Mode</th>
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<th>Frequency</th>
<th>Imaging</th>
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Sharing of Previous Treatment Records

• Minimum Data Elements or Treatment Summary
  + Patient identifying information including date of birth
  + Isodose plots and DVH reports
  + DICOM Image, RD and RS files (make sure to include a plot for import verification.)

• Secure, encrypted email or drop box
  - Caution, some email systems reject emails with links in them.
“The QMP’s scope of practice categorizes medical physics activities into the following areas: Administrative, Clinical services, Education, Informatics, Equipment performance evaluation (EPE), Quality, Safety.”

“Their deep understanding of the performance of radiation equipment and information systems brings value to clinical problem solving and the technology assessment process.”

Initial Steps

1. Identify how and where MDEs are entered in your system currently.
2. Ask around, find out if anyone is pulling Rad. Onc. data in your institution currently. If so, how are they using it? Are they pulling it from the correct place? Talk to your cancer registrars and see if they have issues interpreting the data.
3. Make improvements to how your MDEs are entered.
4. Find ways for off the shelf data sharing. Talk to the EMR vendors and other software developers.
5. Be involved in reporting and infrastructure decisions.