



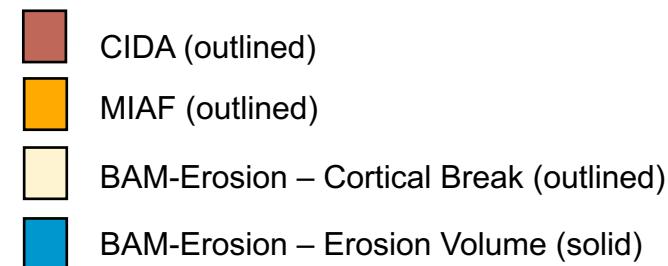
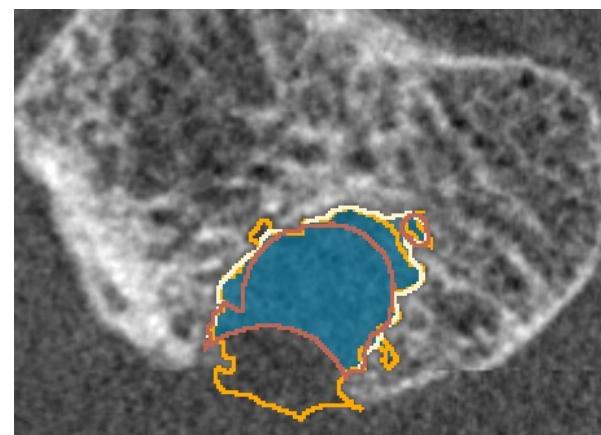
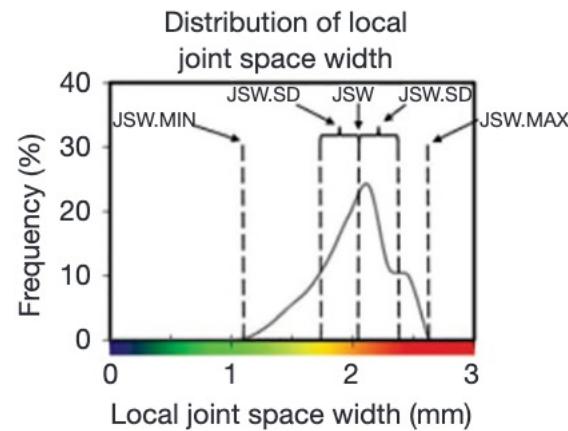
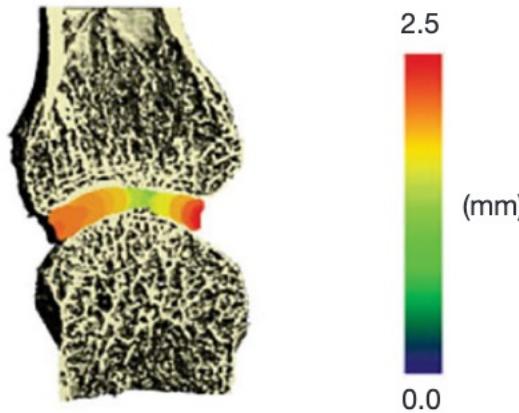
SPECTRA
Collaboration

Developing a repository for metadata: the SPECTRA experience

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Finzel, Kayla Millar, Kathryn Stok, Lai-Shan Tam

Why a repository?

- Ultimate goal is to use HR-pQCT as an outcome for clinical trials in RA
- No standardized tools for erosion analysis
- No benchmark datasets available

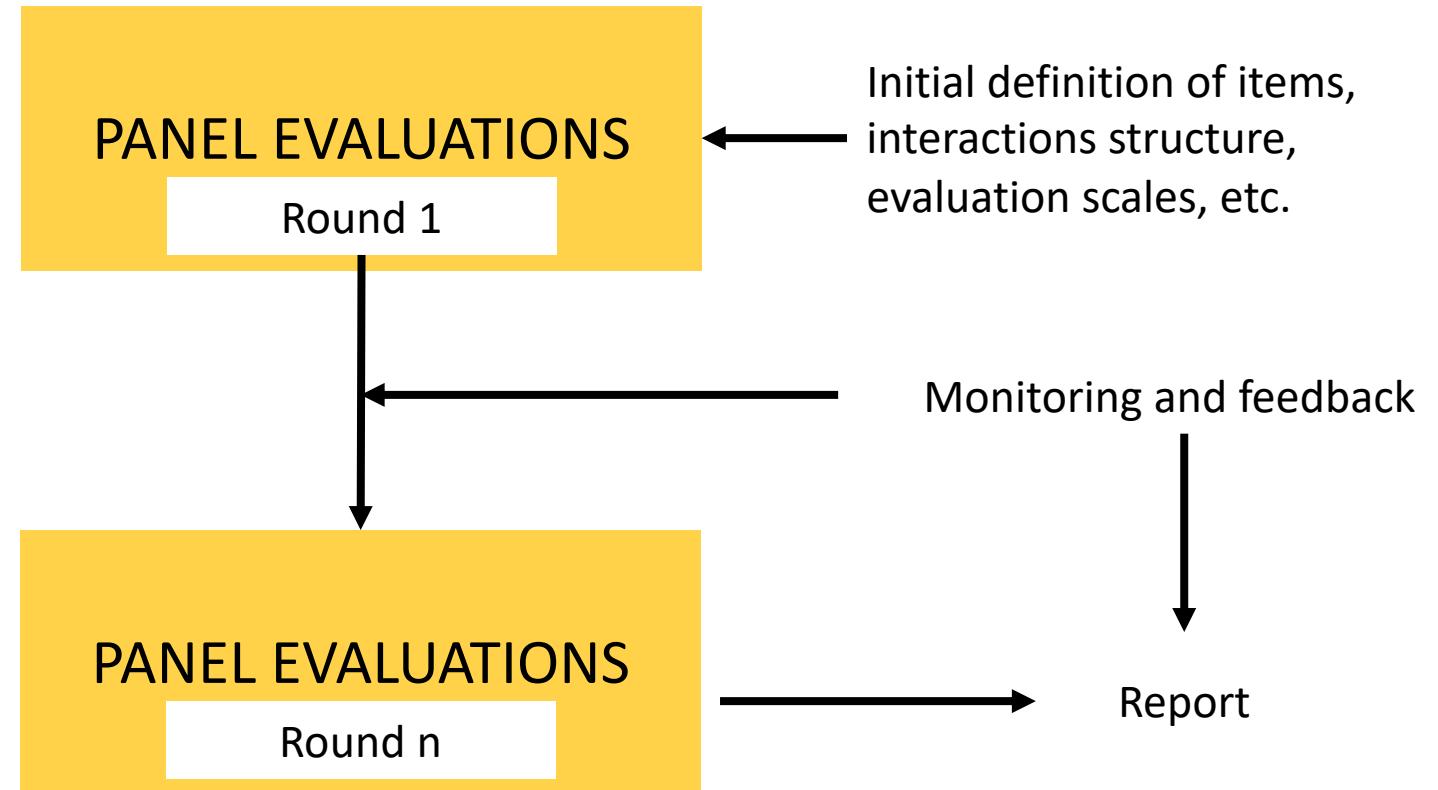


Why a meta-data repository?

- Potential to generate a larger dataset
- Share meta-data, not images
- Enable sharing without violating data protection concerns
- Simpler to implement (?)

What variables should be included?

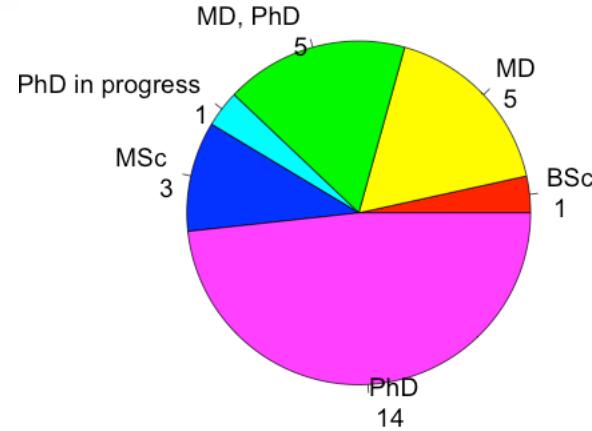
OMERACT:
Delphi Consensus
for Core Outcome
Set Development



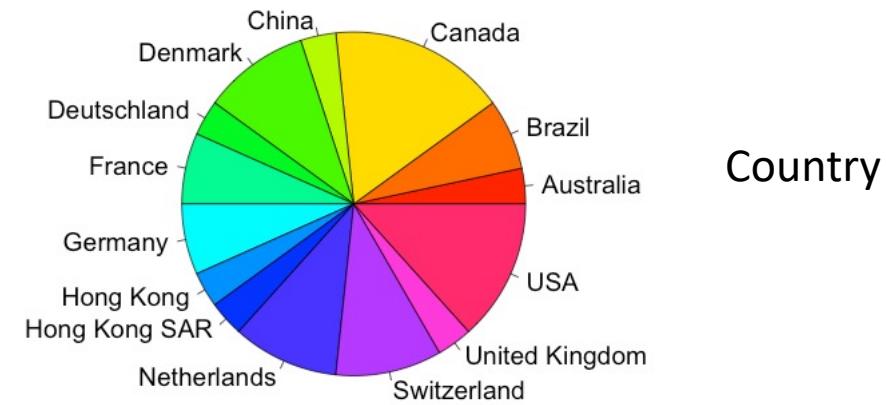
Our method (Round 1)

- Participants: Stakeholders from SPECTRA Collaborations's contact list
- Preliminary variable list decided by SPECTRA co-chairs
 - Demographics, clinical, treatment, serology, patient-reported, study characteristics, imaging characteristics
- Consensus: 75% agreement
- 5 point-Likert scale
 - 1 = not important, 2 = somewhat important, 3 = important but not critical, 4 = somewhat critical, 5 = critical
- Used Qualtrics survey software

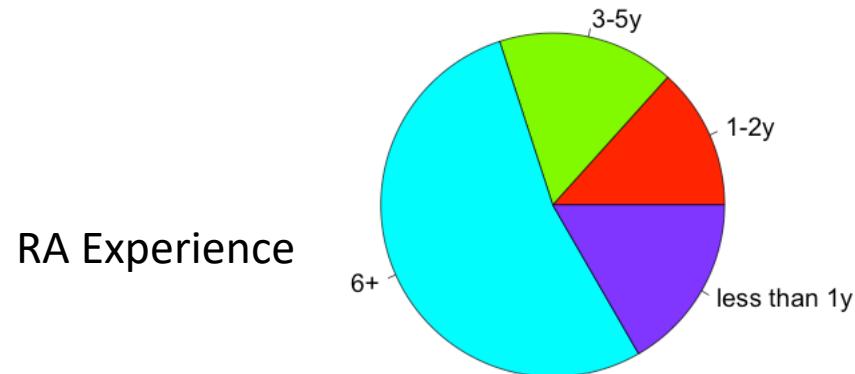
Participant Demographics (n = 30)



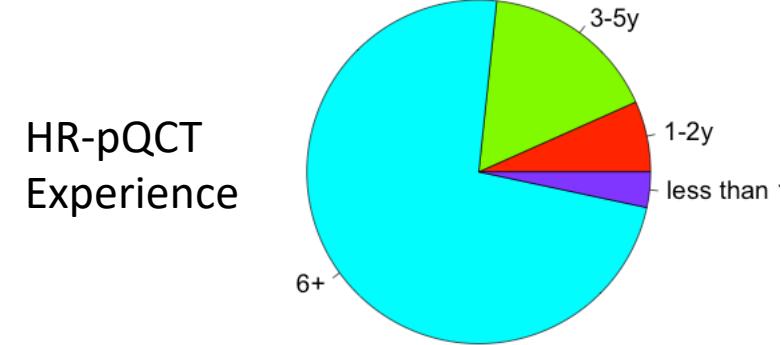
Academic Training



Country

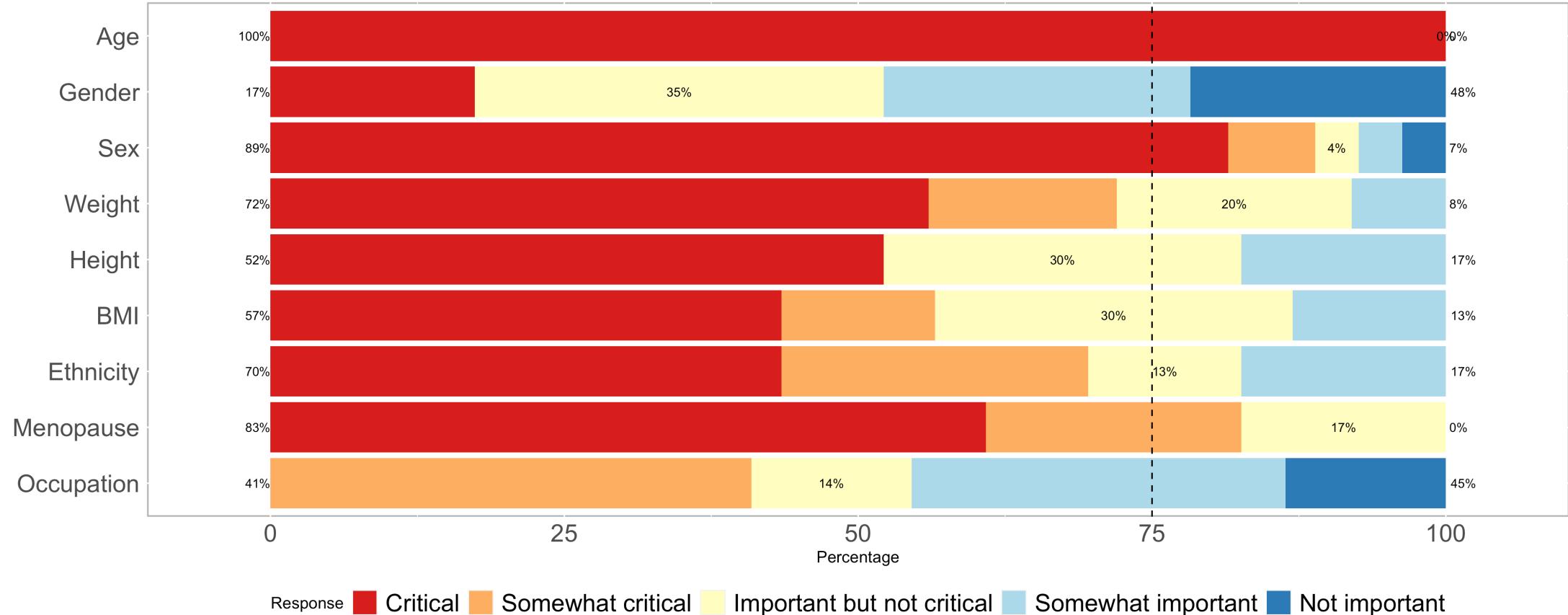


RA Experience

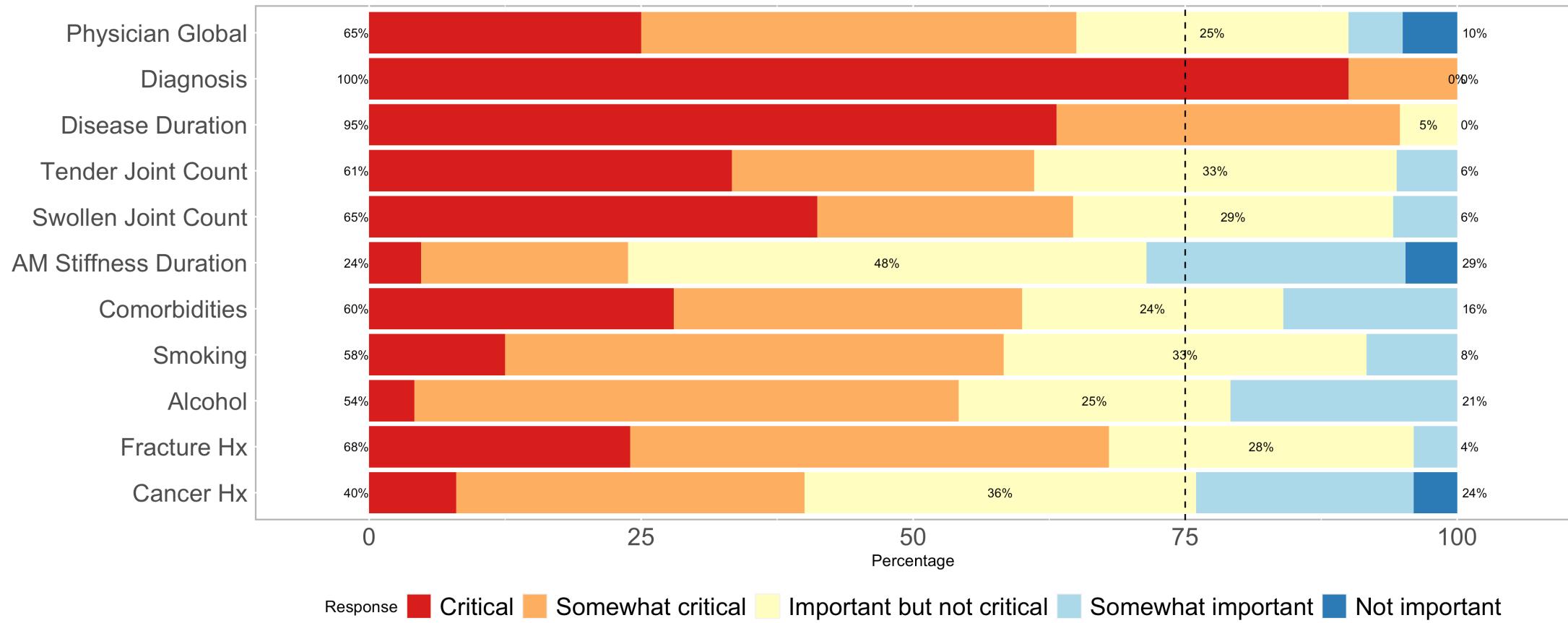


HR-pQCT
Experience

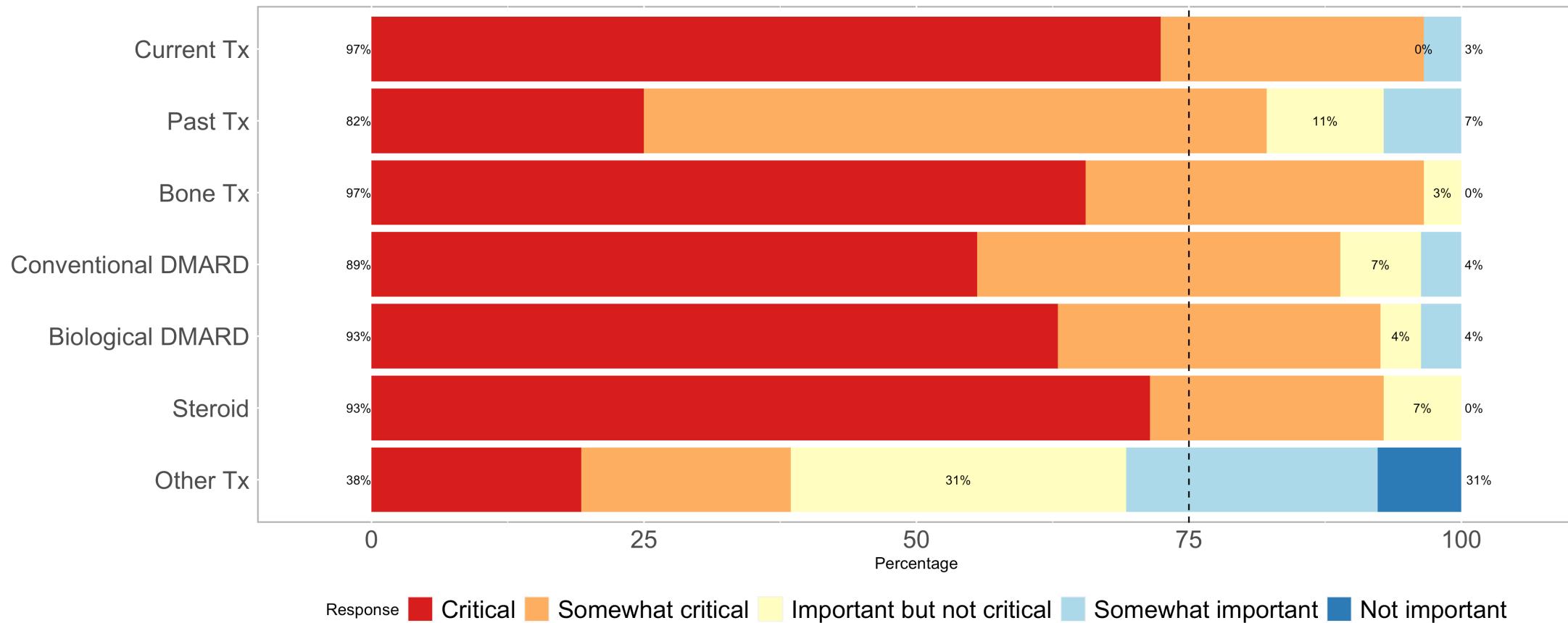
Round 1 Results - Demographics



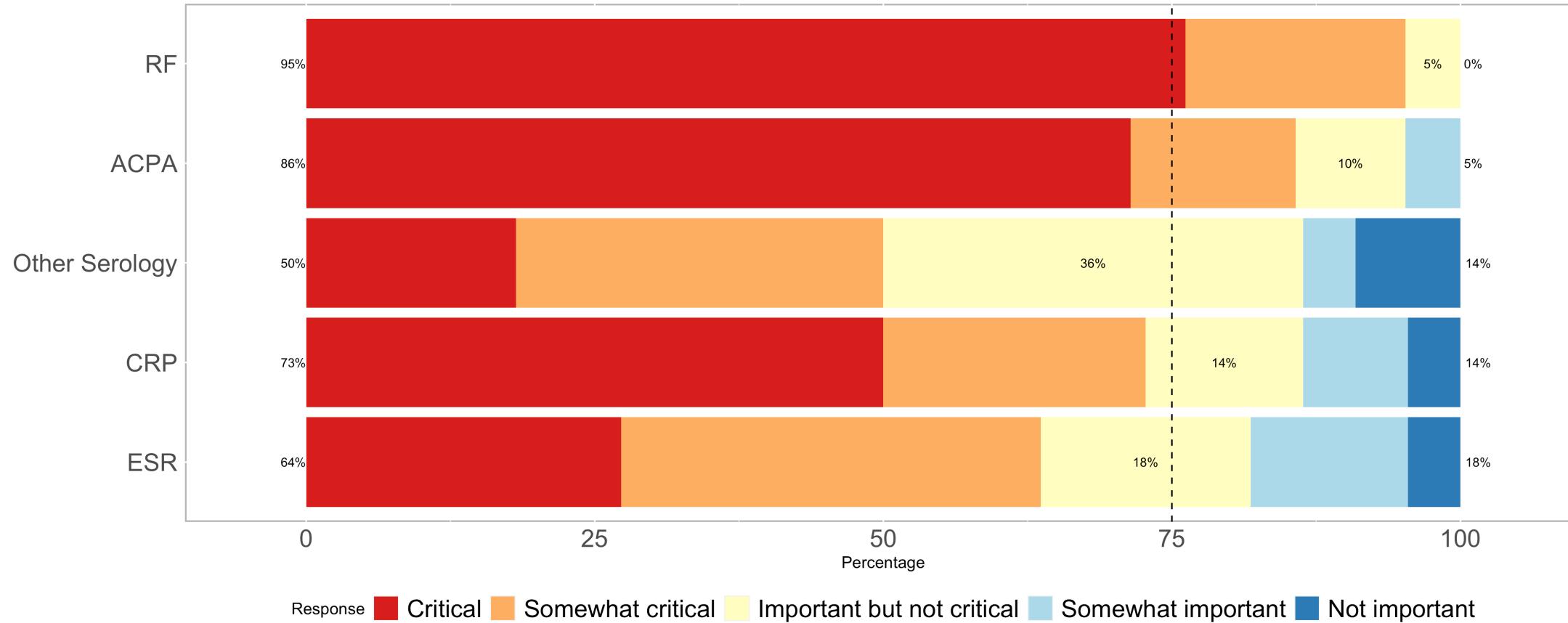
Round 1 Results - Clinical



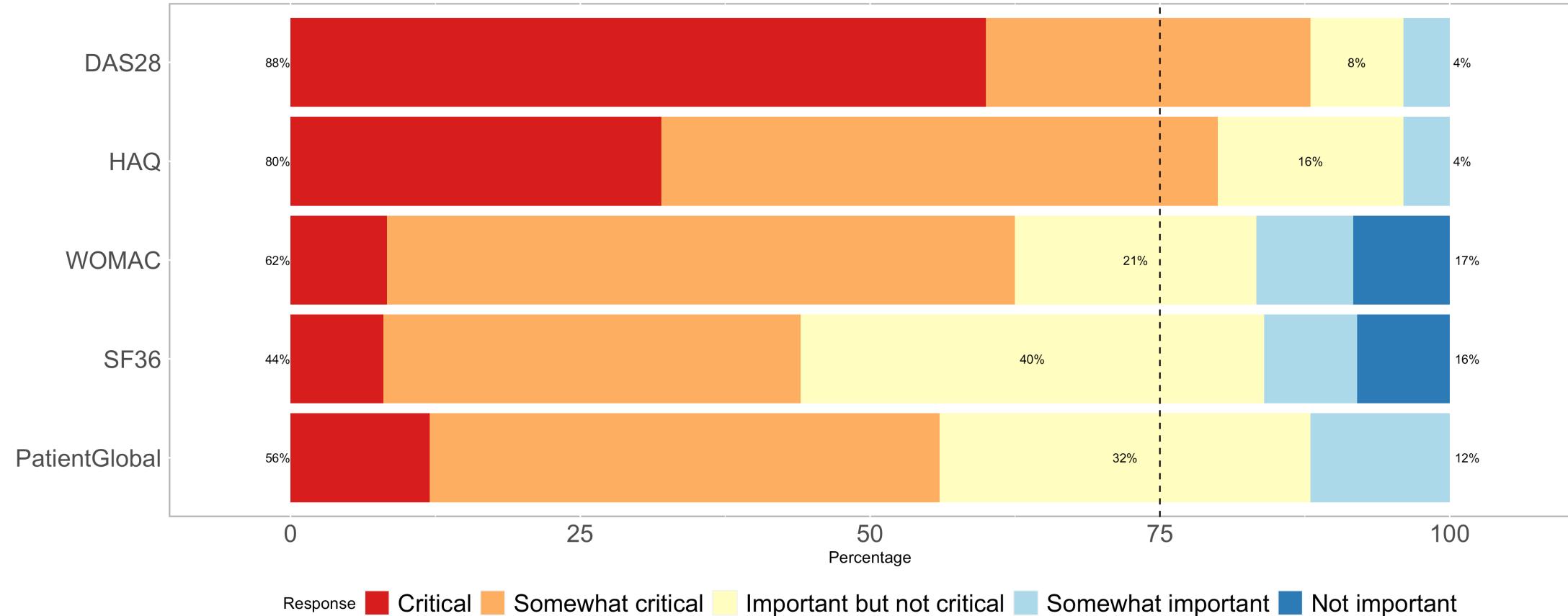
Round 1 Results - Treatment



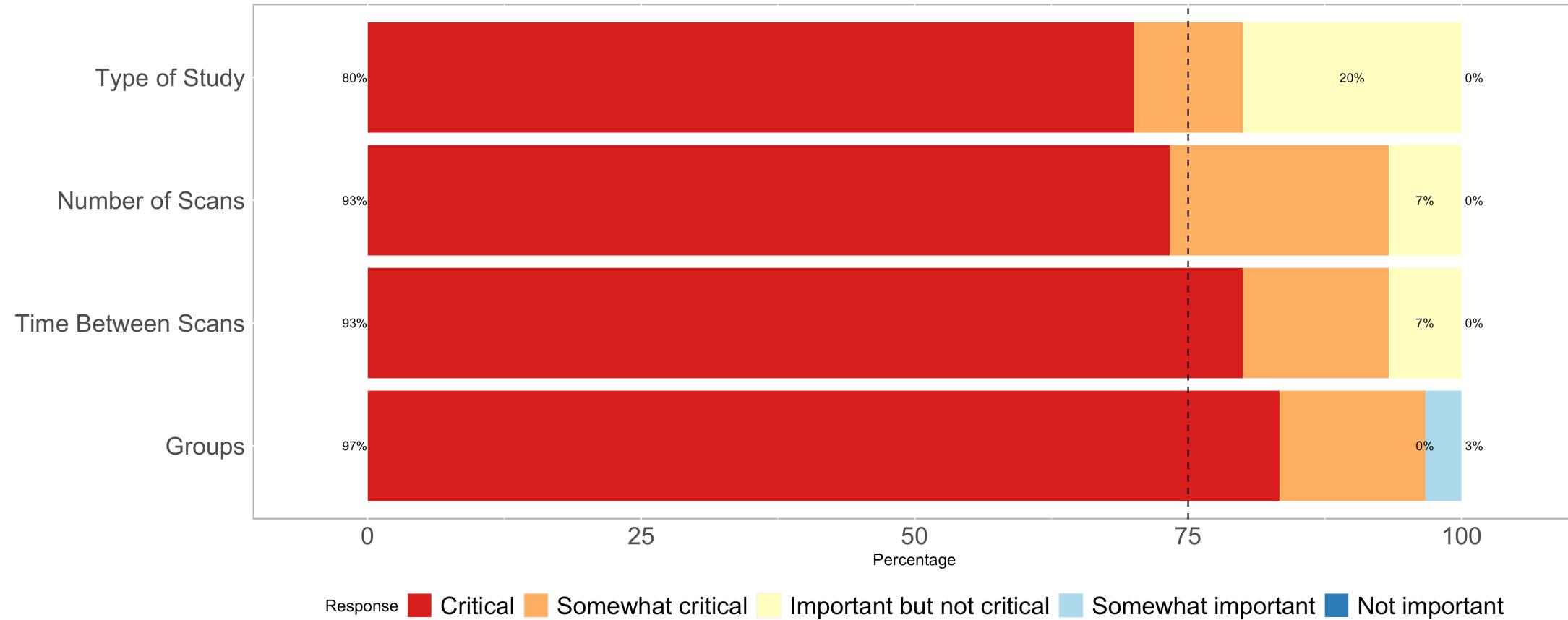
Round 1 Results - Serology



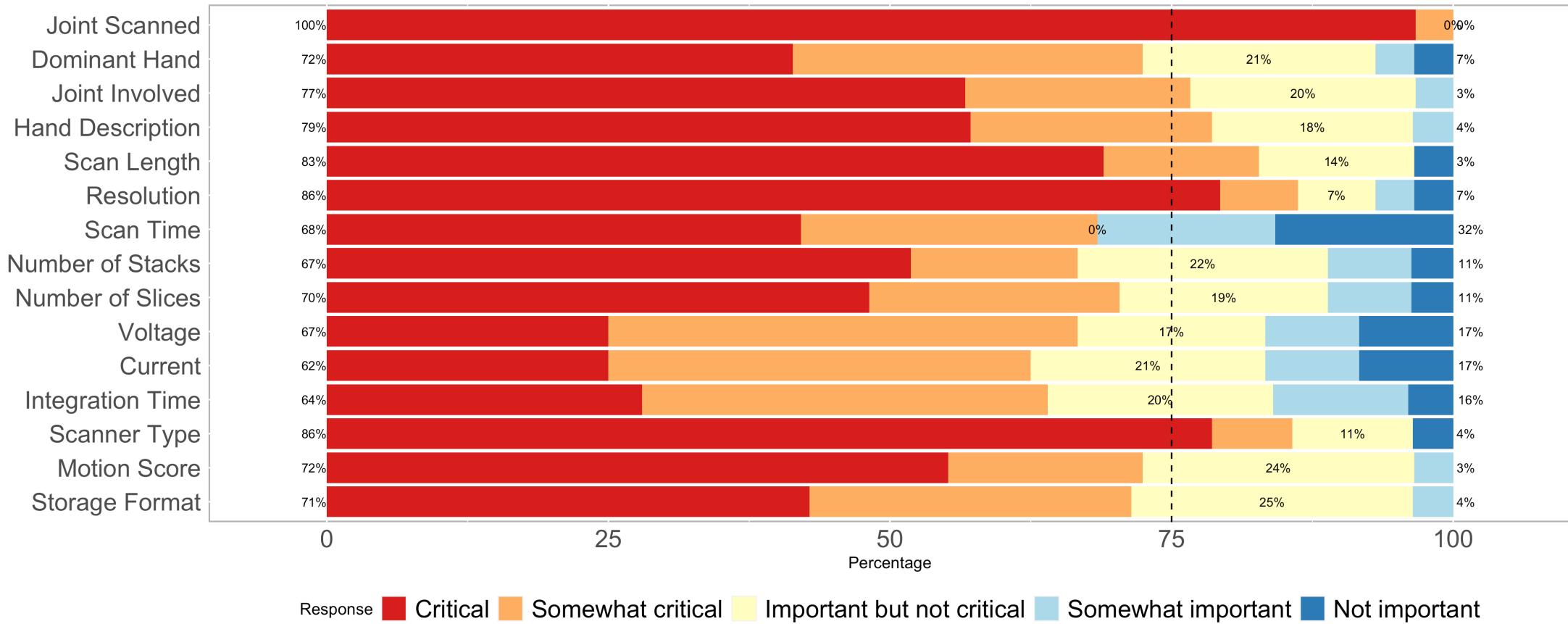
Round 1 Results – Patient Reported Outcomes



Round 1 Results – Study Design



Round 1 Results – Imaging



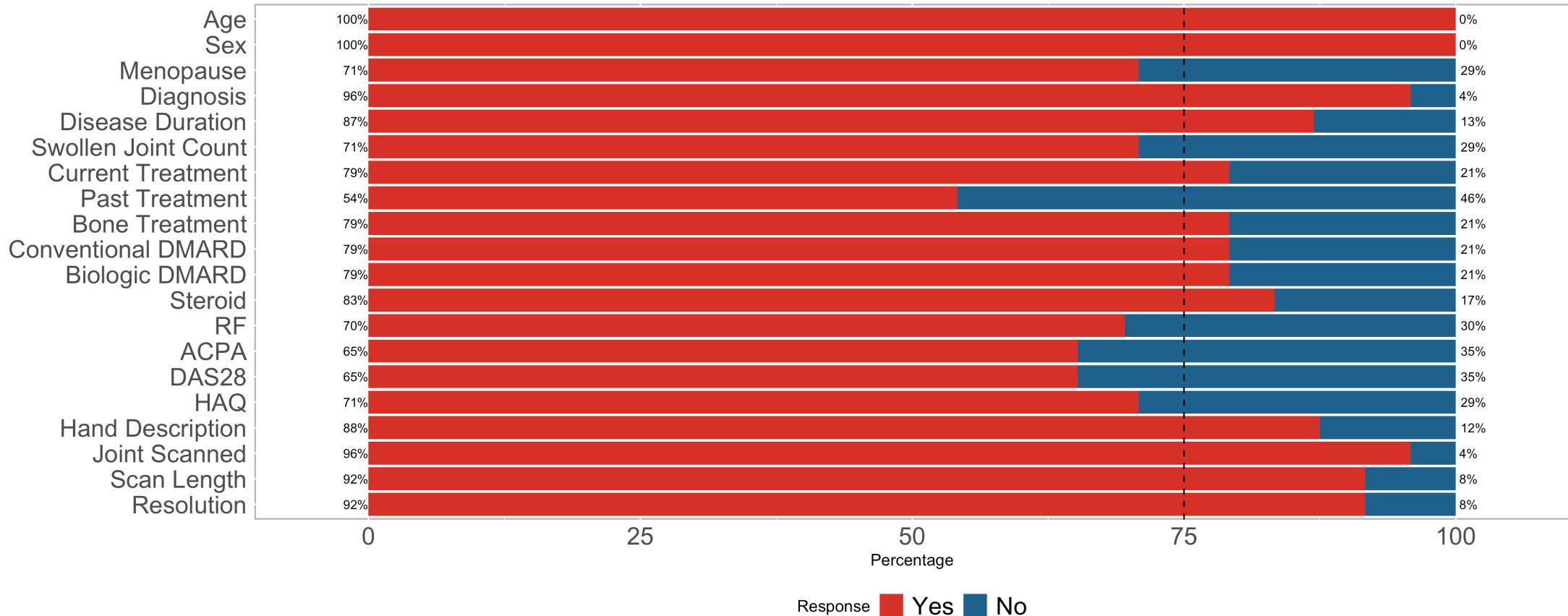
Problems in Round 1

- Method intended for development of Core Outcome Sets (Prospective)
- Highly varied results
- Vary depending on background (clinical vs academic)
- Do participants ALWAYS collect the data? (This data will be retrospective)

Modified Round 2

- For variables that reached consensus, revisit:
 - Do participants always collect the data (Yes, No)
- For revoting variables:
 - Short description of relevance
 - Rating as Mandatory, Optional, Not important
 - Options
 - "May be important but we do not collect this data"
 - Asked about barriers to collecting data

Round 2 Results – For variables that reached consensus: Do you collect this data?



Round 2 Results – Retest variables that didn't meet consensus



Take aways about the process

- Limited participants due to size of community
- Good responsiveness
- A lot of work for a small component
- We didn't ask about data sharing rules

Thoughts about the repository

- Will be time consuming to establish
 - Individual level data vs study summary
- Who will use it?
- How will we maintain it?
- Will it be expandable?

Discussion

- What happens if study doesn't contain a “mandatory” item?
 - (Retrospective vs. Prospective)
- Repository for HR-pQCT vs other modalities
- Image vs meta-data repository

Acknowledgments

- SPECTRA members!
- Kayla Millar
- Stephanie Finzel
- CIHR Planning and Dissemination

