

Follow-up and Treatment Workgroup Progress Report

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Workgroup Activities

1. **Medical Foods – the report will be:**

- Sent to the HHS Secretary as informational
- Posted on the Committee's website
- Submitted for publication in a peer-reviewed journal (abridged version)

2. **Quality Measures Report – dissemination plan/ideas:**

- Posted on the Committee's website
- Identify journals to publish the executive summary (not peer reviewed)
- Consider topic specific articles that build on the report
- Consider what aspects of the report tie into the roadmap project
- There are a variety of audiences that may be interested in the report – does the Committee want to do outreach?

3. **Long Term Follow Up Roadmap – development phase:**

- Consider next steps based upon Kemper and Lam's environmental scan and think about what the different components need to be.

Long-Term Follow-up Roadmap – ideas for moving to an informatics paradigm

- The vision for the roadmap is a “federated” systems approach to LTFU and treatment.
- Core desideratum (*something that is needed or wanted*)
 - Single registry/QI program per disease/group
 - Data consistency
 - “Hub and Spoke” data collection
 - Patient identification and continuity
 - Coordinated research/QI and funding

Discussion Questions

- How can data and registries inform quality measures that can help us improve/inform treatment and follow-up?
- Is there interest in creating an integrated system for quality measures?
- Do we need a core set of data elements that are both disease specific and applicable across diseases?
- How can we ensure newborn screening conditions have a follow-up plan?