



Consensus conference

Protocols

Data collection

Dissemination

Future Plans

ONLINE

READY TO GO!



Survey

Next steps

Friends of CARRA
JDM Practice Survey

Scenarios

N = 11



Team

Cases

What's been done?



JDM Standards of Care Study: GROUP D SURVEY

Exit this survey >>

Survey Monkey

Survey development

Pilot testing

Background

JDM studies

No

Evidence?

Adults

IVIG ✓

MTX/CyA ✓

Fitness Exercise ✓

Leukapheresis/Plasma Exchange ✗

Friends of CARRA



CARRA

Trials

Rare Diseases

Alternative Designs

Plan

1

Friends of CARRA, TMA, TAS, CIHR, Other

Survey of current practice

2

Consensus conference to determine 1 to 3 Rx. protocols

3

NIH, CIHR, Other?

Predictors of Rx response within protocols (incl. pharmacogenomics, etc.)

Comparison of protocols using bias reduction techniques

9 mos

12 mos

24 mos

