

Patient registries

Randomised controlled trials pros and cons

Question to ask before opting for an RCT...

What's your treatment?



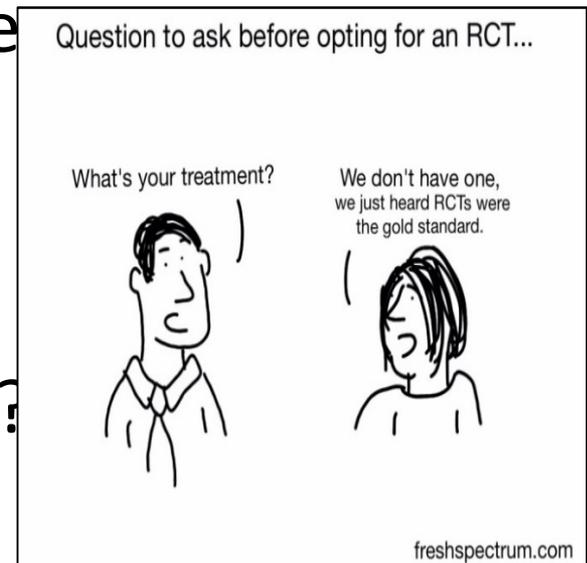
We don't have one,
we just heard RCTs were
the gold standard.



Randomised controlled trials pros and cons

- Disease with indolent course, older patients populations and significant late complications
- Patients change from allocated treatment
- No trial had the objective of controlling either the platelet count or the white cell count
- Acute leukaemia: actual incidence versus actuarial, calculated risk

What else can and have we learned?



What did we learn from MPN registries?

- From the St Thomas' registry we learnt about HCT target in PV
- About pregnancy management
- About benefits of transplantation
- From Spanish registries about the hazards of HU resistance
- Bleeding risk for CALR ET with aspirin

Problems with registries

- May be subject to bias
- May be led by an enthusiast and stop when they stop
- May be limited by geography
- Health care economy does not easily support them