



Summary of Responses to pre-workshop ERN Survey - Clinical Practice Guidelines, Plans and Priorities

19 ERNs responded

• ERN BOND; ERN CRANIO; ENDO-ERN; EPICARE; ERKNET ERN; ERN GUARD-HEART; ERN ITHACA; ERN LUNG; ERN PAED-CAN; ERN EYE; ERNICA; ERN RND; EURACAN; GENTURIS; MetabERN; EUROGEN; RITA-ERN; ERN TRANSPLANT CHILD; VASCERN

Many Questions in this survey were designed to elicit free-text responses: anonymised responses (i.e. free text comments which do not indicate the ERN which provided the feedback) will be included below.

Q3a: Do you intend to generate new CPGs for diseases under your scope?

YES	17
No	0
Not Sure at this stage	2

Q4a: Do you intend to appraise existing CPGs for diseases under your scope

YES	14
No	2
Not Sure at this stage	3

Q5a: Do you plan to use a particular methodology (e.g. AGREE) in your ERN, for elaboration of CPGs?

YES	12
No	2
Not Sure at this stage	5

