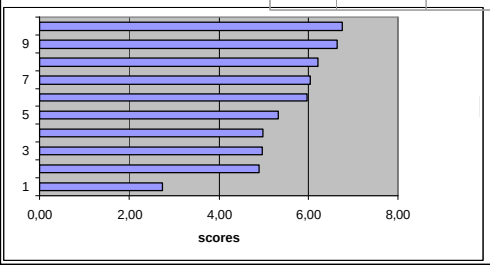
Cystic Fibrosis Neonatal Screening in Europe
Priorities for a Consensus Document

Answers:	total	30
	clinicians	14
	laboratories	16

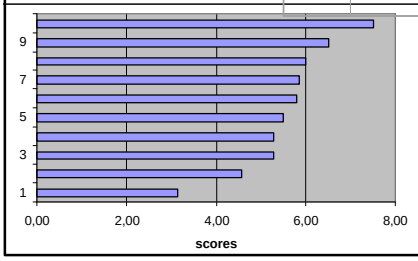
CF NBS Priorities for Consensus ALL

No	score	question
1	2.75	Criteria for CF diagnosis in screened newborns
2	4.89	Best practice for mutation analysis (technical issues, mutations to include or not to include)
3	4.96	Management of atypical cases detected through NBS (e.g. borderline sweat test, and/or one or two non CF-causing mutations)
4	5.00	Best practice for IRT measurement
5	5.32	Best practice for sweat test (technical issues, timing, etc.)
6	5.96	Management of carriers detected through Neonatal Screening
7	6.04	Minimum standards of information to parents of all screened newborns and to parents called for sweat test
8	6.21	Statement of ECFS/EuroCareCF on the necessity of implementing CF Neonatal Screening throughout Europe
9	6.64	Review of advantages and disadvantages of Neonatal Screening
10	6.75	Communication of CF diagnosis: what to say and how to say it



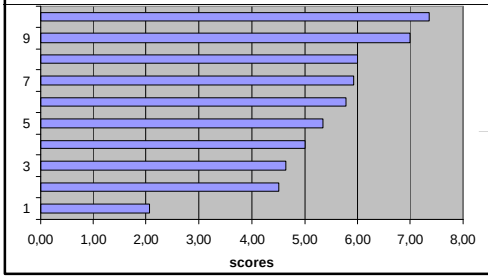
CF NBS Priorities for Consensus LABORATORIES

No	score	question
1	2.15	Criteria for CF diagnosis in screened newborns
2	4.69	Best practice for mutation analysis (technical issues, mutations to include or not to include)
3	4.69	Best practice for sweat test (technical issues, timing, etc.)
4	5.00	Best practice for IRT measurement
5	5.31	Management of atypical cases detected through NBS (e.g. borderline sweat test, and/or one or two non CF-causing mutations)
6	5.69	Review of advantages and disadvantages of Neonatal Screening
7	6.15	Minimum standards of information to parents of all screened newborns and to parents called for sweat test
8	6.21	Statement of ECFS/EuroCareCF on the necessity of implementing CF Neonatal Screening throughout Europe
9	6.64	Management of carriers detected through Neonatal Screening
10	6.75	Communication of CF diagnosis: what to say and how to say it



CF NBS Priorities for Consensus CLINICIANS

No	score	question
1	2.15	Criteria for CF diagnosis in screened newborns
2	4.69	Management of atypical cases detected through NBS (e.g. borderline sweat test, and/or one or two non CF-causing mutations)
3	4.69	Best practice for IRT measurement
4	5.00	Best practice for mutation analysis (technical issues, mutations to include or not to include)
5	5.31	Best practice for sweat test (technical issues, timing, etc.)
6	5.69	Management of carriers detected through Neonatal Screening
7	6.15	Statement of ECFS/EuroCareCF on the necessity of implementing CF Neonatal Screening throughout Europe
8	6.21	Communication of CF diagnosis: what to say and how to say it
9	6.64	Minimum standards of information to parents of all screened newborns and to parents called for sweat test
10	6.75	Review of advantages and disadvantages of Neonatal Screening



Other topics suggested

Clinicians:

-non-DNA based screenings

-process of disclosure and making the diagnosis

-minimising psychological distress

-the way the above topics are reflected in the aims and structure of the screening protocol (sensitivity (especially for mild cases), specificity, minimising carriers, coping with uncertainty, etc) and **how to design a protocol** accordingly

-management of patients with CF identified by screening

-management of false positives (not necessarily carriers)

-organization of the screening procedure from prenatal information until diagnosis

-early respiratory and nutritional management

Laboratories:

-criteria to extend mutation analysis