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Variation in prognosis given by feto-maternal units in fetuses with neurological abnormalities.

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The 'Magnetic Resonance Imaging (MRI) to enhance the diagnosis of fetal developmental brain abnormalities *in utero*' (MERIDIAN) study showed improved diagnostic accuracy and confidence for detecting fetal neurological abnormalities compared to ultrasound. The additional information provided by in utero MRI altered prognosis in 44% of women, although clinicians reported it changed prognosis in only 24%.(1, 2) The reasons for this discrepancy are not clear, and the MERIDIAN study did not report whether the neurodevelopmental prognoses given to women varied between clinicians or were accurate.

We contacted one clinician at each of the MERIDIAN Feto-Maternal Units and asked what percentage chance of normal neuro-developmental outcome they would give pregnant women for 5 fetal neurological abnormalities (table 1). There was general agreement for isolated mild ventriculomegaly,(3) but wider variation for posterior fossa abnormalities, with the suggested chance of normal outcome for one condition ranging from 10 to 90%.

Estimating long-term neuro-developmental outcome based on antenatally detected neurological abnormalities is challenging due to limited high-quality data. Even where data exists, it rarely tells the full story: percentages are blunt tools, and terms like "good, moderate or severe", and "low, moderate or high risk" are subjective. Furthermore, outcome studies can erroneously place children with neurological diagnoses into an abnormal group; for example, a child with mild unilateral cerebral palsy with normal cognition, function, quality of life, independence and participation may be categorised as "severely abnormal" based on the diagnosis of cerebral palsy alone. Previous research has shown families do want to know risk, but also best and worst-case scenarios to build a picture of what it is like caring for a child with those difficulties. This information helps families assess whether they have the emotional and financial means to provide for the child's possible needs.(4)

Our data highlights a number of areas that need further study, including analysis of what variation exists in the risks given to women for specific fetal brain abnormalities, and how well these agree with published evidence. Long-term outcome data into later childhood and adolescence is also essential, especially because outcomes assessed at 2-3 years of age may be poor indicators of later abilities.(5) Such outcome measure should utilise commonly available tools for motor, cognitive and behavioural measures, as well as measures of independence, participation, quality of life, and parental quality of life and stress.

Table One: Percentage chance of normal outcome given to pregnant woman and their families by a clinician in 14 different feto-maternal units for 5 abnormalities

Respondant	Isolated Ventriculomegaly 10- 12mm	Posterior fossa abnormality (not Dandy Walker Abnormality)			
		Isolated hypoplasia of the cerebellar vermis	Unilateral hypoplasia of the cerebellar hemisphere	Isolated Cisterna Magna	Isolated Blake's Pouch Cyst
1	No reply	I would not give good outcome – would be cautious: defects may be mild but delay likely	I would not give good outcome – would be cautious: likely deficit but not as marked unless inferior vermis is involved	Very good outcome	Very good outcome
2	95%	Don't know	Don't know	Greater than 95%	Unknown
3	No reply	50%	80%	95%	90%
4	90%	80%	60-70%	Greater than 95%	90%
5	90%	50%	50%	95%	99%
6	95%	Worrying	Excellent	Excellent	Good
7	90%	95%	70%	95%	95%
8	90%	No reply*	No reply*	No reply*	No reply*
9	95%	80=90%	Not sure: carries a variable outcome from normal to developmental impairment	80-90%	50%
10	95%	80%	75%	90%	95%
11	90%	30%	10%	90%	90%
12	No reply	75%	50%	99%	No reply
13	95% If resolves, 90% of persists	90%	90%	97%	97%
14	90%	75-80%	40-50%	90-95%	90-95%

*Responder indicated they would not give a figure, but would refer on for further advice to another Feto-Maternal Unit

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