Newborn screening is generally conducted without consent, on the premise that having one of the disorders screened constitutes a medical emergency for which there are proven benefits of very early treatment. Screening for disorders with insufficient data on benefit must be conducted with consent. Our Early Check research project offers free, voluntary screening to every birthing parent in North Carolina, but getting valid consent at a population level remains a formidable barrier. Efforts to ensure voluntary enrollment and to improve parental understanding could inform future decisions about the role of consent in NBS and the viability of a “second-tier” consented platform of conditions that do not meet rigorous standards for NBS but are of great interest to families and still offer potential benefits.

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