Preterm infants have immature internal organs and often need help with breathing, feeding, and other life support. Those who survive may suffer all health or disability in childhood, which could potentially continue to adulthood. Even modest improvement for these infants and their families would be important. Clinical research may not fully address the uncertainties in treatment and care that are of greatest importance to service users and clinicians. This research adapted a mixed-method approach developed by the James Lind Alliance to establish Priority Setting Partnerships (PSP). We recruited 44 clinical and service users’ organisations across UK and Ireland from April 2011 and formed a Steering Group (SG). An on-line survey was conducted from March to September 2012. A total number of 1,050 participants started the survey, while 548 of them (service users: 57%; clinicians: 30% and both 12%) suggested about 200 research unique uncertainties. While we received feedback from clinicians of various specialties (neonatologist: 28%, nurse: 25%, obstetrician: 18%, midwife: 12% and others 10%). Most service users were white British and middle class. Service users asked about aetiologies, interventions and outcomes for pre-pregnancy, antenatal (2), perinatal (18), postnatal (58) and other care (20), revealing interests in a broad range of issues surrounding preterm birth. If research agendas are to serve the interests of service users at higher risk of preterm birth, there is a need to improve ways of engaging service users from ethnic minorities and disadvantaged backgrounds.