From The Haemophilia Society

• Has all of the relevant evidence been taken into account? The Haemophilia Society believe all the relevant evidence has been taken onto account, but may not have all been interpreted in the way we would agree with.

• Are the summaries of clinical and cost effectiveness reasonable interpretations of the evidence? For adults with Genotype 1 we can't understand why people with cirrhosis have been excluded from ledipasvir-sofosbuvir, as the licence states '12 weeks may be considered for patients deemed at low risk for clinical disease progression and who have subsequent retreatment options'. By excluding this option we believe some of the sickest patients will be disadvantaged. We acknowledge this would not be a common situation, however it would be more inclusive to allow clinicians to prescribe this if they felt it to be in the best interest of their patient. This is particularly pertinent for the bleeding disorder community, as they are at risk of requiring considerably higher Factor treatment costs if their liver is cirrhotic, so anything to prevent further progression and the risk of a liver transplant would be both ethical and cost effective.

• Are the provisional recommendations sound and a suitable basis for guidance to the NHS?

• Are there any aspects of the recommendations that need particular consideration to ensure we avoid unlawful discrimination against any group of people on the grounds of race, gender, disability, religion or belief, sexual orientation, age, gender reassignment, pregnancy and maternity? We are aware that many of the bleeding disorder community have genotype 4 Hepatitis C, due to NHS treatment. We would suggest that they be considered as a special group eligible for treatment when they have cirrhosis and/or prior treatment failure. This is due to the considerable cost of Factor treatment they require, particularly if they require a liver transplant. Many of this patient group have had extensive prior treatment and to exclude them form this new and beneficial treatment could be seen as discriminatory.

[redacted], The Haemophilia Society