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Location	England
Organisation	The Hepatitis C Trust
Conflict	Yes
Declaration of interest	Gilead fund The Hepatitis C Trust for a project (approx 1% of Trust income) and provide funding for a joint industry, clinician patient working group to which the Trust contributes an equal amount.
Comments on individual sections of the ACD:	
	The Hepatitis C Trust would like to thank the Committee for the opportunity to comment. We would also like to say that we, as patients and patient representatives, felt listened to and heard during the first Committee meeting. We would like to make three comments as regards the Committee's preliminary decision: 1. As we said during the scoping workshop, we are in principle against looking at sub-populations. Our belief is that for almost any technology a sub-population can be found for which that technology would not be cost-effective. Sub-population analysis then becomes a way of excluding patients. We are particularly concerned about this in the current appraisal because we do not believe the impact of hepatitis C is properly captured in much of the QoL data nor do we think the cost-effectiveness analysis can exclude the cost of onward transmission* (we have consistently submitted to NICE about this over the years). The ICERs across the various sub-populations in this appraisal vary widely but we believe the sub-populations for whom the ICER is highest (e.g. those truly interferon intolerant with genotype 1 or 3 for whom 24 weeks of Sofosbuvir might be needed and those not intolerant with genotype 2) are small. Since there is no robust data on the number of people truly intolerant to interferon, we are requesting the Committee to ask the clinical experts for their opinion as to this at the next Committee meeting and on the basis of that make a determination for Sofosbuvir across the whole population, not by sub-population. We believe that, given the relevant sizes of the sub-populations, Sofosbuvir is cost-effective across the whole population and should be recommended on that basis. 2. We have considerable anecdotal evidence that the side-effects of interferon and ribavirin treatment are deterring people from taking treatment, which is one of the reasons only 3% of those living with hepatitis C are treated each year (Hepatitis C in the UK, PHE 2013). An important factor in this, we believe, is the length of interferon/ribavirin treatment, at between 24 and 48 weeks. We believe that many more people will consider a

	12 week course of treatment with interferon or 24 weeks without, who would not otherwise do so. For them the true comparator is not interferon and ribavirin but rather no treatment. This is likely to decrease ICERs. We are requesting the Committee to ask the clinical experts for their opinion as to this at the next Committee meeting. 3. Very few prisoners with hepatitis C are treated. One reason for this is that the majority of those with hepatitis C are convicted of drug-related crimes or acquisitive crimes related to drugs and consequently receive relatively short sentences; the length of expected time in prison, if it is less than the 24 to 48 weeks required for a course of treatment, excludes them from treatment, since there is too little follow-through after prison to ensure continuity of treatment in the community. The practicality of a significantly shorter course of treatment available in most cases with Sofosbuvir will change that and allow treatment for those who would not otherwise be able to access it. We are requesting the Committee to ask the clinical experts for their opinion as to this at the next Committee meeting. This therefore has an important equalities component. In addition, if the reality is that most of these prisoners would with Sofosbuvir be able to access treatment they would not otherwise be able to do, then the comparator, as in point 2 above, should be no treatment, not interferon and ribavirin, which again is likely to decrease ICERs. *There are 5,000 to 10,000 new infections per year in England (PHE unpublished data), almost all of them transmitted by people currently infected
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