National Institute for Health and Care Excellence

Sofosbuvir for treating chronic hepatitis C [ID654]
Consultation on decision to amend the deferred funding

Royal College of Nursing

Introduction

The Royal College of Nursing (RCN) has been invited to comments on the proposal for extending the statutory period for deferred funding of the above appraisal

RCN Comments

The RCN is in agreement that the demand for Hepatitis C treatment will increase significantly in the context of availability of next generation therapies, which will change the landscape of Hepatitis C over the next 12 month period and beyond. We are however as a country already well behind in terms of identification of HCV and treatment numbers. In view of this there are many existing and emerging examples of excellent innovative service delivery, the best provision of which is delivered as close to the patient as possible.

There are a number of documents relating to minimum service specifications for HCV treatment delivery. Many hospitals reach these specifications and prior to the early access scheme (EAS) were delivering HCV treatment with high standard auditable outcomes being demonstrated. This pathway continues for standard of care therapy (Pegylated interferon, ribavirin and for some addition of Boceprevir or Teleprevir).

Unfortunately for many centres not involved with the EAS there have been a proportion of patients unable to, or unwilling to travel to specialist centres to have their treatment instigated and monitored. For some patients a door to door journey to receive their hepatitis C treatment, may be in the region of 2 hours travelling time each way, not accounting for poor transport links in some areas. This has made the EAS a postcode lottery of treatment for some individuals.

The proposal of NHS England developing further specialist treatment centres providing a centralised resource for patients is but an extension of the EAS and being put in place predominantly for budgetary reasons. Many of the centres currently running EAS programmes are 'holding patients' for newer therapies and some centres have an extremely large number of patients waiting. In addition the centres involved with EAS are also centres collaborating with the HCV registry which opens up access to clinical research that many other hospitals cannot gain. Again this raises concerns regarding access and equity to treatment giving some patients' excellent access to trials and depriving others.
In particular the intravenous drug using HCV population appear to be most disadvantaged currently. In fact they should be one of the most important groups to treat as the most health gain will be achieved due to the reduction in the incidence of HCV.

With regards to the need for increasing staff and resources we have to remember that in fact the clinical delivery of newer therapies will be much easier with significantly fewer side-effects to monitor, less time on treatment for patients and less intervention with clinic appointments. Even in the patients with established cirrhosis where complications may be more frequent this is no different to complications seen with cirrhosis in previous therapies and continued close liaison with tertiary centres will remain important.
With regards to potentially deferring patients with mild disease to await therapy consideration should be taken with regards to previous NICE documentation and recommendations (NICE technology appraisals TA106).

The suggestions made by NHS England may lead to further health inequalities with regard to parity and equity of access to the recommended contemporary treatment modalities. It is vital that

treatment can be offered as close to the patients home as possible. If hospitals can offer a set specification standard for HCV treatment they should be allowed to deliver HCV treatment. Serious consideration by NHS England to expand the number of treating centres is vital. Data could be fed back to a regional HCV network for monitoring and audit. The networks responsibility would be to develop treatment guidelines on appropriateness of therapy and compare outcome data to national standards.

As the health service infrastructure and facilities are most definitely in place, and we do not believe otherwise. We believe that NHS England should not be driving the NICE mandate to decide on treatment in this way.

To be able to have such dramatic results in Sustained Viral Response (SVR) with Sofosbuvir, and the impact this will have on QALYs for patients will end up being a huge cost savings to the NHS with reduced problems of cirrhosis/HCC and liver transplantation –

We don't think it makes sense to delay treating hepatitis C with Sofosbuvir.