

## Patient and Public Involvement (PPI) in Research – Case Study

**Provided by:**

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**How patients and the public were involved**

STOP-HCV ([www.stop-hcv.ox.ac.uk](http://www.stop-hcv.ox.ac.uk)) is one of 13 consortia funded by the Medical Research Council through their Stratified Medicine Initiative. The consortium is using stratified medicine (an approach which subdivides patients into groups based on their risk of developing specific diseases or their response to particular treatment) as an approach to establish the most effective treatments for patients with Hepatitis C Virus (HCV) infection. The STOP-HCV work programme integrates several different studies all aimed at generating models that can be used in the clinic to improve patient treatment and care.

STOP-HCV brings together clinicians and scientists, in collaboration with industry and the Hepatitis C Trust. The Hepatitis C Trust is the national UK charity for hepatitis C and its Chief Executive, Charles Gore, is a valued member of the consortium. Charles sits on the STOP-HCV Project Steering Committee, which meets every 3 months and STOP-HCV has funds (£15,000) dedicated to support patient engagement activities.

At a local level, research outputs from STOP-HCV are discussed at 6-monthly patient forum meetings held at the John Radcliffe hospital. These interactive meetings are attended by the local hepatitis research team and hepatitis patient groups (e.g. the Swindon hepatitis C patient support group) and provide a valuable opportunity to engage patients in research.

**The impact of involving patients and public in the study**

Having Charles Gore as a member of the STOP-HCV Project Steering Committee has provided valuable insights from patients' perspective, and been important in shaping the research programme. He has provided valuable input towards the design and development of STOP-HCV clinical studies, for example a short-duration treatment study to explore stratification in patients with mild disease and a cirrhosis study to identify prognostic biomarkers for disease progression in patients with severe disease.

In addition he has provided valuable advice and input, from a patient's perspective, to the development of the consortium's Health-Related Findings policy. The nature of the research being undertaken within the STOP-HCV project is likely to lead to the discovery of incidental health-related findings. This policy relates to the consortium's position on the feedback of such health-related findings to patients.

**The importance of involving patients and the public in research**

From an academic/clinical/industrial perspective it is extremely important to gain insights from patients' perspectives to inform the STOP-HCV work programme and ensure the ultimate goal of improving patient treatment and care remains at the forefront of the project.

From patients' perspectives (and feedback received) it is extremely valuable to have the opportunity to ensure that patient benefit remains at the centre of the project and that stratification/personalised medicine is presented correctly - i.e. ensuring that it is not used as a tool to deny certain patient groups access to treatment.

**The biggest challenges in PPI and what might help to overcome them**

As well as Chief Executive for the Hepatitis C Trust, Charles Gore works extensively with UK government departments and the NHS, championing the patient perspective, and works closely with a number of international organisations with interests in hepatitis (e.g. the World Health Organisation and the World Hepatitis Alliance – for which he is currently President). Increasing demands on his time makes it difficult for him to devote time to the numerous hepatitis-related research projects underway in the UK. To help alleviate this, the Hepatitis C Trust is appointing a Deputy Chief Executive whose role will be to support these research activities. The funds dedicated to patient engagement activities within the STOP-HCV award will be used to support this post in part. Having funds of this nature is critical to help support patient engagement and continued engagement throughout the duration of a research project of this nature.