Using Electronic Patient Record Data to Investigate Viral Hepatitis

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Viral Hepatitis

• Inflammation of the Liver caused by one or more unrelated virus hepatitis A,B,C,D and E.

• Chronic Infection with Hepatitis B or C Virus can lead to Liver Cirrhosis and Hepatocellular Carcinoma.

• Both are most commonly transmitted via contact with infected blood.

• Hepatitis D virus can only replicate if co-infected with Hepatitis B.

• Hepatitis E can causes an acute mild hepatitis and is most commonly spread via contaminated food.
The image illustrates the leading causes of death globally from 1990 to 2013. The causes are categorized into communicable and neonatal, non-communicable, and injuries. The bar chart on the right shows the trend of deaths (thousands) for low-income and lower-middle-income countries and upper-middle-income and high-income countries from 1990 to 2013.

NIHR Health Informatics Collaborative: Objectives

• To produce exemplar research projects.
• Provide modern infrastructure to allow researchers to share and exploit secondary care data for research.
• Establish rich longitudinal datasets in the NHS and BRCs.
• Common governance and PPI framework (including consent).
• Future proof the solution with automatic data capture where ever possible.
• Improving electronic patient records.
• Establishing comparability of data between BRCs.
• Creating interoperability between IT systems within and between BRCs.
• Industry engagement.
The Challenges of the Viral Hepatitis Theme

• Large dataset covering 4 distinct diseases with unique research questions.

• 5 Different NHS Trusts with differing patient populations, clinical services and IT infrastructures.

• Fast moving and competitive research environment.

• A need to develop appropriate governance for ethically collecting and sharing data on vulnerable patients.

• First exemplar research questions are:
  • HCV: What influences treatment outcomes with the new Direct Acting Antivirals?
  • HBV: The determinants of HBsAg loss and eAg seroconversion in treated patients?
  • HEV: Who gets it and why?
Conceptual Architecture NIHR HIC, Prof Jim Davies
Key Requirements for the OUH Hepatitis Clinical Research Database

- Import Legacy data (mostly excel spreadsheets or csv files).
- Easily update datasets to reflect changing research questions.
- Robust security and user roles.
- Custom reporting and exporting of data.
- Patient-centric manual entry / editing of clinical data.
- Automatic import of data from OUH Middleware.
Patient Centric Data Entry

- The standard LabKey workflow for data entry is dataset centric.

- Manual entry and editing of data is a key requirement of Hepatitis Clinical Research system.

- Research Nurses and Clinicians wanted a way of entering data which makes sense to them and follows their workflows.
LabKing: Rule over your subjects

• Built using LabKey Javascript API.

• Can be used with any datasets but requires to be pointed at an enrolment dataset.

• Code available at github.com/spikeheap/labking
### Subject Record

**Cohorts**
- Autoimmune Hepatitis
- Hepatitis B
- Hepatitis C
- Hepatitis E
- Other
- No Cohort

**Searching**
- Participant ID, NHS Number

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**Participant Groups**

Showing 3 of 3 participants

Please select a participant...
Automated importing of clinical data
On-going Research using OUH Hepatitis Research Data.

- Incidences of Hepatitis E in patients with underlying liver disease in Oxford Cohort.
- Integration of longitudinal clinical data with viral and host genetic data to better understand Hepatitis C and B.
- Development of HCV Vaccine.
- Integration with viral sequencing to better understand resistance to Hepatitis C Direct Acting Antivirals.
Future Work

• Collection of minimum dataset from all sites for NIHR HIC Project.

• Analysis of data for exemplar research questions.

• Partnerships with industry partners in collaborative analysis of data.

• Further Development of Hepatitis Clinical Research System.
  • Reporting
  • Dashboard views of key data
  • Integration with further clinical systems
  • Automating quality control
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