HepHIV 2014
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HIV and Viral Hepatitis: Challenges of Timely Testing and Care

A consensus definition of late presentation of viral hepatitis for medical care

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On behalf of the working group

The situation

- Over 13 million adults are living with hepatitis B and 15 million with hepatitis C in the WHO European Region – indicating a huge burden of treatment and care (WHO 2013 estimated numbers)
- Most remain undiagnosed, however no official statistics present the total number of diagnosed in Europe
- Effective treatments for HBV and HCV are recent developments with great impact on the possibility to treat people with HBV and HCV if diagnosed timely

The public health challenges

- It remains unknown whether current testing policies and strategies succeed in testing the right people at the right time
- Linkage to the health system able to provide comprehensive care (i.e. to reliably classify the degree of liver disease and provide treatment when indicated) is unknown
- Consequently, a large (but yet undetermined) proportion of the chronically infected population enters care only once they have developed clinical symptoms
- Others that remain asymptomatic enter care *after* the time in the course of their chronic viral infection where initiation of treatment would have provided them with an optimal treatment response

What type of data should the consensus definition be composed of?

- The data upon which it is based needs to be readily available as part of routine care at clinics that provide care
- All referrals should be classified
- Should be applied at the time when patients are entering the treatment centres able to evaluate the stage of liver disease and provide treatment if indicated

Why do we need consensus?

- There is no definition globally
- We need a definition
- We need to convince policy makers and health authorities to use the definition
- They need to understand that we agree
- Surveillance structures are struggling to have robust and harmonised data collection, meaning only one standardised definition

What will it be used for? Surveillance

- Harmonisation of the definitions used in surveillance systems is a critical component in order to standardize and compare surveillance data.
- Make the problem ”visible”
- Improve the quality of reported data and the comparability of data between countries
- Monitor evolution by official bodies and academic organisations
- Support improvement of models to estimate the number of undiagnosed infected people

What will it be used for?
Improving testing strategies

- Monitor increased testing of the population and refining of referral systems to and structures (including trained staff) of medical sites able to provide comprehensive care
- Quality control marker for public health policies and initiatives promoting earlier diagnosis
- To identify risk factors for late presentation to target testing strategies in a standardised way
- Define who is likely to present late?
- Evaluate changes in numbers presenting late for care

- The definition is not intended for defining treatment initiation
  - It is assumed that most (if not all) persons presenting late will be offered treatment
  - It is possible that also persons not presenting late maybe offered treatment
  - These decisions are made by medical experts at the clinic where the patient is entered for care

- Indicate the optimal time to start treatment
  - YES
  - NO

What should a definition of late presentation be used for?

- To harmonise the definitions used in surveillance systems
  - YES
  - NO

- Improve reporting of surveillance data and enable country comparisons
  - YES
  - NO

- Make the problem ”visible”
  - YES
  - NO

- Monitor evolution by official bodies and academic organisations
  - YES
  - NO

- Monitor increased testing of the population and refining of referral systems to and structures (including trained staff) of medical sites able to provide comprehensive care
  - YES
  - NO

- Quality control marker for public health policies and initiatives promoting earlier diagnosis
    - YES
    - NO

- To identify risk factors for late presentation to target testing strategies in a standardised way
  - YES
  - NO

- Define who is likely to present late?
  - YES
  - NO

- Evaluate changes in numbers presenting late for care
  - YES
  - NO

How to evaluate the use of the definition?

- Evaluating testing strategies:
- If >50% of the diagnosed persons are presenting late – need for improved testing strategies
- Goal: 0% late presenters!

The process

- The need for a definition was discussed by the HepHIV2014 Organising Committee
- All relevant stakeholders were invited to participate, including patient advocacy groups, health policy-makers, international health organisations, surveillance experts and medical experts
- A series of teleconferences has taken place in September 2014 in order to derive a first draft version of the consensus definition(s)

A proposal for a definition

- **Late presentation:** persons presenting for care with F3 or F4 fibrosis.

A proposal for a definition

- **Late presentation:** persons presenting for care with F3 or F4 fibrosis.

- Do you agree with this proposal for a definition?
  - YES
  - NO

Presentation with advanced disease

- **Presentation with advanced disease**: Persons presenting with symptoms related to liver disease (HCC or cirrhosis presenting with significant biochemical evidence of chronically impaired liver function or symptomatic portal hypertension)

Why two definitions?

- Advanced disease
  - Imminent need for treatment
  - No technology needed, only based on symptoms
- = all clinics are able to ascertain this definition

Presentation with advanced disease

- **Presentation with advanced disease**: Persons presenting with symptoms related to liver disease (HCC or cirrhosis presenting with significant biochemical evidence of chronically impaired liver function or symptomatic portal hypertension)

Do you agree with this definition?

- YES
- NO

Recommendation

The working group behind the proposal recommends:

- using the momentum that increased efforts are needed to support a continued consensus building
- That the agreed definition should not change in the forseable future, since not linked to how early to start treatment, but used as a benchmark

Next steps

1. Consult stakeholders about the proposed consensus definition in a public hearing phase
2. Publish a brief position paper focusing on the definition, the rational behind it and its potential implications
3. Advocate for its use by researchers of papers as well as surveillance institutions

Points for discussion

European consensus working group on late presentation for Viral Hepatitis Care

- Erika Duffell, ECDC
- Maria Buti, HEPBCPPA
- Hilje Logtenberg, ELPA
- Nikos Dedes, European AIDS Treatment Group (EATG)
- Stefan Wicktor, Team Leader Global Hepatitis Programme, WHO Regional Office for Europe
- José Gatell, University of Barcelona
- Charles Gore, Hepatitis C Trust, World Hepatitis Alliance
- Jeffrey V Lazarus, Health System Global, Rigshospitalet, University of Copenhagen
- Jens Lundgren, CHIP, Rigshospitalet, University of Copenhagen
- Eberhard Schatz, Foundation De Regenboog Groep (FRG) representing Correlation Network, Hepatitis C Initiative
- Pol Stanislas, EASL
- Irene Veldhuijzen, Public Health Service Rotterdam, the HEPscreen project
- Brian West, European AIDS Treatment group (EATG)
- Jürgen Rockstroh, University of Bonn