HEPATITIS C AWARENESS IN KENTUCKY'S POPULATION THROUGH ADVOCACY AND LEGISLATION

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EXECUTIVE SUMMARY:

C Team for KPHI (Kentucky Population Health Institute) 2016-17 consists of seven public health professionals from all across Kentucky joining hands in working together on the vital issue of Hepatitis C infection affecting the community at large in the Commonwealth. This seven member enthusiastic group hails from various disciplines of public health ranging from Epidemiology, Nursing, Clerical and Maintenance from different health departments in Kentucky. This is a real strength for this group having diverse public health expertise from different geographic regions of the state.

Hepatitis C is a serious liver disease caused by the Hepatitis C virus (HCV). Some people get only a short-term, or acute, infection and are able to overcome the virus without treatment. However, about 80% of people who get infected with HCV develop a chronic, or lifelong, infection. Over time, chronic Hepatitis C can cause serious health problems including liver damage, liver failure, and even liver cancer. Kentucky is at the center of an injection drug use epidemic that has brought with it the highest HCV infection rate in the country. CDC estimates that there were 2.7 to 3.9 million people living with chronic hepatitis C in 2014. Hence, our project mainly focuses on increasing awareness of Hepatitis C infection in the population through legislative actions and advocacy. To that we tried contacting legislators. Speaker of the house and different agencies (like KPHA (Kentucky Public Health Association)/KDHA (Kentucky Health Department Association) with position statement for Hepatitis C and current Hepatitis statistics for the state. This group also tried to implement Hepatitis awareness in LHD programs like (Health Access Nurturing Development Access) HANDS and (Syringe Exchange Program) SEP.

C Team aims to achieve funding for Hepatitis educators and/or promote Hepatitis awareness through other existing programs in Kentucky. This will be an ongoing project and aim to outlast our KPHLI graduation.

INTRODUCTION/BACKGROUND:

Hepatitis C is a virus that infects the liver resulting in symptoms that range from extreme fatigue, jaundice and joint paint to no symptoms at all. Because the infection is often asymptomatic, many people do not know that they are infected and do not seek medical care. In 75% to 85% of cases the infection will become chronic, without treatment 60% to 70% will progress to chronic liver disease. If not treated 5% to 20% of cases with chronic liver disease will progress to Cirrhosis, and in 1% to 5% it will lead to death.

The virus is transmitted from person to person, when blood from an infected person comes into contact with the blood of an uninfected person. Prior to 1992 it was spread through blood transfusions and organ transplants. However, in 1992 blood banks began testing the blood supply. Currently, transmission is primarily through the sharing of contaminated needles, or drug paraphernalia.²

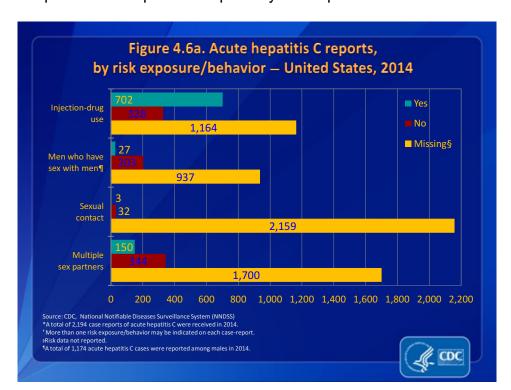
In 2014 forty states reported a total of 2,194 cases of acute hepatitis C (case rate 0.7 cases per 100,000 in the population) Those affected were predominately young, white, had a history of IDU, previously use of an opioid, and lived in small rural towns with a higher incidence seen in Appalachia.³

Figure 4.2. Incidence of acute hepatitis C, by age group — United States, 2000–2014

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Graph 1 Incidence of acute hepatitis C by Age Group. 3

Over the last several years Kentucky, like much of the rest of the country, has experienced an increase in heroin use. Along with the increase in injection drug use (IDU) came an increase in reported cases of Hepatitis C (HCV).

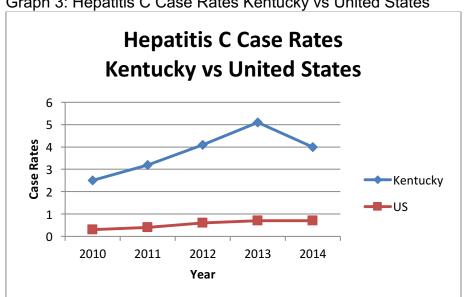


Graph 2 Acute hepatitis C reports by risk exposure/behavior.3

Between 2012 and 2014 the Kentucky Department for Public Health, along with the local health departments, conducted a Hepatitis C testing pilot. During this pilot program 78% of those testing positive listed IDU as a risk factor.⁴

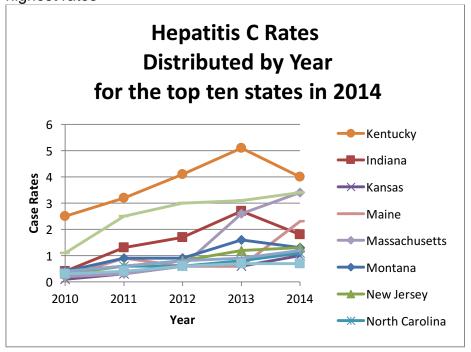
A study conducted by Edlin, Eckhardt, Shu, Holmberg, and Swan and cited by the CDC in the 2014 Viral Hepatitis Surveillance Report, estimates that there are 4.6 million people in the United States who are positive for HCV antibody, indicating past or current infection, with 3.5 million of those being currently infected.^{3,5} Nationally the number of cases reported increased more than 2.5 times between 2010 and 2014. While in some states this increase is due to enhanced surveillance funded by the CDC, Kentucky did not receive this funding and the higher number reported in this state is seen as a true increase in new cases.³

Kentucky has a high burden of HCV, in fact Kentucky has reported the highest case rate among reporting states in 2010 through 2014. See Graph 3 and 4 for illustration of the data obtained from the CDC Viral Hepatitis Statistics and Surveillance report. The Commonwealth reported 176 cases of acute hepatitis C, in 2014, a case rate of 4.0, which was the highest case rate, reported that year, almost six times the national case rate of 0.7.



Graph 3: Hepatitis C Case Rates Kentucky vs United States

Graph 4 Hepatitis C Case Rates 2010 to 2014 for the US and states with the highest rates

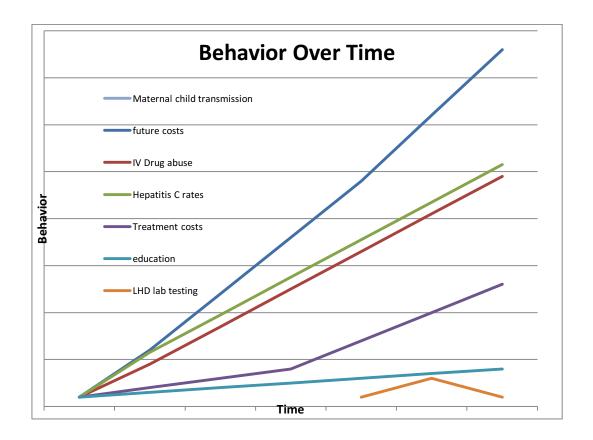


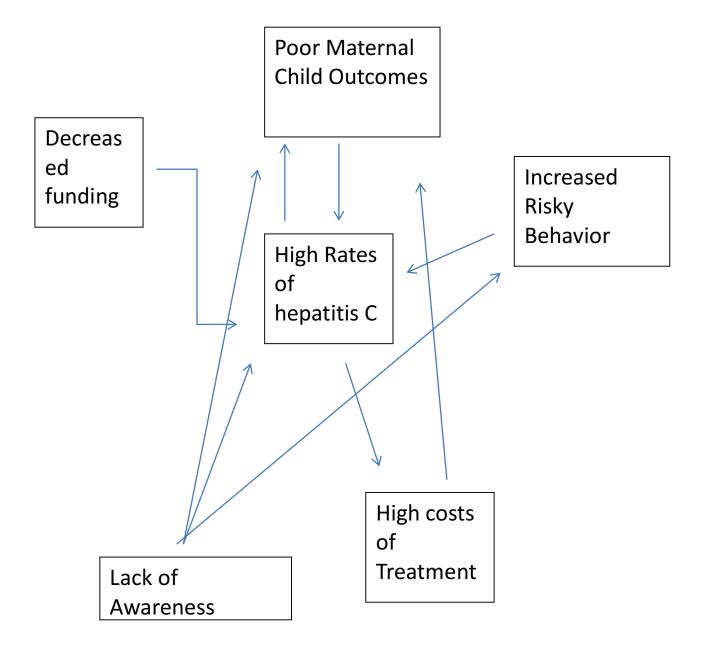
The cost of caring for a person with HCV differs according to the age at the time of infection. Razavi, Elkhoury, Elbasha, Estes, Pasini, and Poynard (2013) looked at the burden and cost of chronic Hepatitis C in the United States in a study funded by Merck & Co. Basing their study on the 2011 prevalence and the assumption that the number of HCV cases peaked in the United States in 1994, they determined that the total healthcare cost for Hepatitis C in the US in 2011 was 6.5 billion dollars. They expect the cost to peak in 2024 at 9.1 billion dollars. The majority of the costs calculated were for compensated liver disease since treatment costs were excluded from the study (6). Treating a person for Hepatitis C infection can range anywhere from 56,000 dollars to 87,000 dollars for a 12 week course of medication. This cost estimate does not include any other health care costs. In 2014 the Kentucky Medicaid Program spent approximately 50,000,000 dollars to treat HCV patients. With this allotment they were able to treat only an estimated 900 cases.7 While Kentucky does not require reporting of nonacute cases of HCV, some areas do track the local cases. Northern Kentucky is an eight county region of the Commonwealth where all cases, acute and nonacute, are tracked. In 2015 Northern Kentucky reported over 1200 cases. At the low end of the cost for medications it will cost well over 60,000,000 dollars to treat just the cases reported in Northern Kentucky that year.

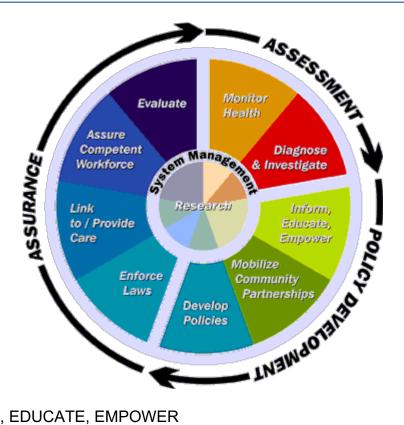
Infants are at risk of contracting this infection from their hepatitis C virus infected mother at birth. According to the CDC there is a 6% chance that a baby born to a hepatitis C positive mother will also be infected. The higher the viral load the higher the chance that the baby will be infected. Interventions such as Caesarian sections have not been shown to decrease the risk of transmission to the baby. This raises concerns about the number of women of child bearing age that are HCV positive and untreated. Nationally the number of cases among women of this age group increased 22% between 2010 and 2014. In Kentucky the case rate for women of child bearing age increased over 200% during the same time period. Nationally the proportion of children born to HCV positive mothers increased 68% during this time; in comparison the proportion of children born to HCV positive mothers in Kentucky increased 124%.

Problem Statement: Why, despite having the highest rate of acute hepatitis C in the nation, is there a lack of information of Hepatitis C in the Kentucky population.

Graph 5: Behavior Over Time Graph







#3 INFORM, EDUCATE, EMPOWER

The C Team researched and compiled Hepatitis C resources for policies that are in place, prices of treatment of Hepatitis C, statistics of acute and chronic cases of Hepatitis C. This research empowered the C Team in our project of health promotion and advocacy for Hepatitis C.

The team received approval to put the CDC's Hepatitis C pamphlet in the HANDS resource packet for new families as recommended by Steve Bing, Executive Director of KHDA.

Since the C Team has formed; many counties throughout Kentucky continue to be approved for the needle exchange program.

#4 MOBILIZE COMMUNITY PARTNERS

Members of the C Team have made contact with Public Health Officials at the state and local level, County Health Department Directors, Representative of KDHA, and KPHA to mobilize our efforts to eradicate Hepatitis C.

#5 DEVELOP POLICY

The C Team's Master Change Project is a public health stepping stone for Health promotion and Hepatitis advocacy to address the rise in Hepatitis C infection.

PROJECT OBJECTIVES/DESCRIPTION/DELIVERABLES:

The goal of the C Team is to increase the public awareness of the Hepatitis C epidemic in Kentucky through health promotion and advocacy efforts. We will consider any policy development or adopted position by government agencies to be a success. This project will have an end date but we do not consider that it will be complete because efforts to promote awareness and advocacy will continue past our time in KPHI. We consider our deliverables to be:

- 1. A position statement that has been and will be presented to different individuals and agencies
- 2. Team members' meeting with Congressman Hal Rogers' Field Representative in Somerset
- 3. Team members' meeting with State Rep. Jeff Hoover in Russell County
- 4. Team members' meeting with Steve Bing, Executive Director KPHA, KHDA.
- 5. Collaborating with Kathy Sanders, Adult Viral hepatitis Prevention Program Manager to provide fact sheets to public
- 6. Targeting pregnant women in the HANDS program with information about Hepatitis C
- 7. A survey of local health department directors to assess willingness to promote Hepatitis C if funding were available
- 8. The LCDHD shared Hepatitis C information on their website and Facebook page.

METHODOLOGY:

The C Team began by planning to create a "tool kit" to provide information to the public through already existing websites and agencies. After assessing what information was available to the general public about Hepatitis C and exploring the accessibility of the information, the team determined that a wealth of information already exists. The team found that the CDC had numerous public service announcements and fact sheets easily found on their website. The group also found that Kathy Sanders, and other public health workers, are valuable assets in Kentucky's fight against Hepatitis C and stand ready to disseminate information to the public, if funding and opportunities are available. After this assessment, the team shifted focus to attempt to advocate with various groups to use the information that is already available to increase public awareness.

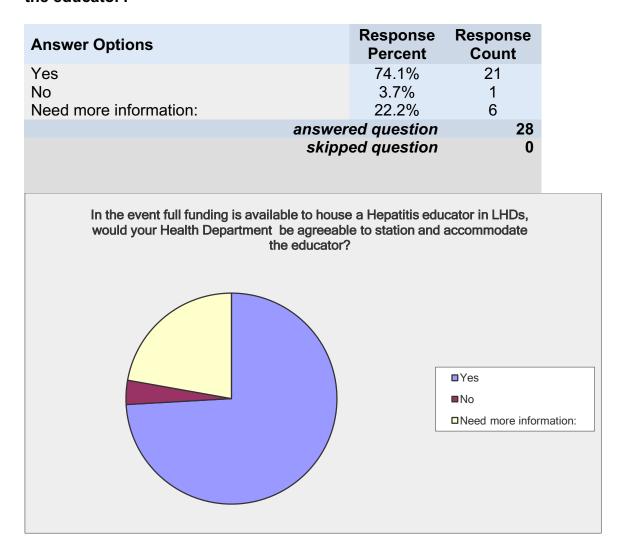
With the focus now being on using available resources to promote awareness, the team began meeting with different groups to advocate for health promotion. The team developed a position statement that we hoped to have adopted by the organizations we were meeting with. Part of the team met with Congressman Hal Rogers' Field Representative, Carlos Cameron, in Somerset. Another group met with State Representative Jeff Hoover in Russell County. Some team members met with Steve Bing (KPHA/KHDA). We also included Kathy Sanders (KDPH) in a conference call with the team to discuss information available and avenues to

promote it. The team was able to get permission to provide pregnant women enrolling in HANDS in Lake Cumberland District and Franklin County with a fact sheet about Hepatitis C in the resource packs given to each participant. The team wanted to evaluate the willingness of health department directors to promote Hepatitis C awareness if funding was available to them. A survey was developed and sent to the directors to answer that question.

RESULTS:

LHD Director Survey (Jan2017)

In the event full funding is available to house a Hepatitis educator in LHDs, would your Health Department be agreeable to station and accommodate the educator?



Our survey result shows that over 74% of Local Health Department Directors are agreeable to house a Hepatitis Educator, provided funding is available.

CONCLUSIONS:

The conclusion of our project was March, 2017. The C Team, after meeting with various groups and conducting the survey of local health department directors, concluded that the need for public awareness about Hepatitis C is great and the desire of public health personnel and government agencies to tackle this issue is present. The lack of funding seems to be the greatest obstacle to progress on this topic. After our meetings and discussions the C Team believes that if funding could be made available for promoting awareness of Hepatitis C risks and ways for prevention the cost would be easily off-set by the savings in treating fewer Hepatitis C cases.

LEADERSHIP DEVELOPMENT OPPORTUNITIES:

Connie Arnold, RN, BSN

I did not have clear expectations when I started at the first KPHI summit. I enjoyed learning more about myself and my colleagues through the emergenetics profile. I found that I scored at a very low level in expressiveness. This was not a surprise to me but reinforced my thinking that I do need to express myself more for various reasons. If I am able to express my expectations and praise more often to my team, I can help build a stronger and more confident team. I can also decrease my own frustrations if I feel my opinions are put forth and heard. I hope to use the knowledge and skills I have gained through KPHI to be a more effective team leader.

Lisa Brown, RN

As a nurse, I have the need to fix things and please everyone. Although I know this is not always an option, I have learned thru this experience with KPHLI is that it's ok that I can't please everyone or fix everything. I have realized that even though somebody doesn't agree with you or you agree with them, it doesn't have to change the relationship you have with that person.

This experience has not changed the person I am but rather has allowed me to see "the big picture" on how I react/handle situations. I feel more confident making decisions, better prepared to deal with daily situations, and be more assertive when needed.

Rudrani (Ronnie) Ghosh, MBBS, MPH

I am very grateful to Jessamine County Health Department for giving me this yearlong KPHI opportunity to develop myself as a team member and a leader in both professional and personal life. I enjoyed the retreats, networking, webinars and team meetings. I got to know my strengths and at the same time focus on my weaknesses. KPHI also helped me to understand myself and how others perceive ME. It definitely provided me with leadership qualities that will outlast this program schedule. I was also fortunate enough to work on a very vital community issue as my Change Master Project. This project helped me to develop my skills and knowledge as an epidemiologist and a public health professional. I shall cherish the memories of this teamwork in many years to come and shall continue to develop myself as a Scholar in public health issues both in the state and abroad.

Allison Griffiths

I do believe that KPHLI has helped me become a better team player. My strengths and weaknesses have been pointed out. Some of this was painful. I can now work on my weaknesses and improve my strengths. The things that I have learned from this experience will help me in the future both in my professional and personal life. I plan to be a better leader through communication and the right attitude.

Dustin McGowan

The past year working with KPHLI I have learned how to work and communicate with others. Developing skills I normally wouldn't have used. As a maintenance supervisor I deal with a great number of people and personalities. I have a desire to please everyone and at times is not possible. This experience has helped me to understand how to deal with co workers and a broad range of situations. Im thankful for the opportunity and hope to utilize what I have learned in the future.

Vicky L. Poplin, RN

I requested to attend the KPHIL program to improve my communication skills in my professional career. The 360 and emergenectics profile allowed me to look at my strengths and weaknesses. My plan permits me to move forward and to make changes as needed. The goals I have set and my experience with the C Team will help me to improve my communication skills in my professional career.

Joyce Rice, RN, BS, MSPH

During the past year working with KPHLI has been a rewarding and enlightening experience. The trainings, reading assignments, and personality tests have allowed me to build on skills I already have, and to develop new skills. Working on a subject that I feel passionate about with a group of passionate people has been a rewarding experience. They have taught me that by working as a team so much more can be accomplished. The hard work of this team those in authority are now talking about this subject and the changes that can occur. The residents of Kentucky are lucky to have these dedicated people working on their behalf.

REFERENCES

- (1) Hepatitis C FAQs for Health Professionals CDC Viral Hepatitis- Hepatitis C. Information website. https://www.cdc.gov/hepatitis/hcv/hcvfaq.htm. Last updated July 21, 2016. Accessed September 2016.
- (2) Zibbell, J.E., Iqbal, K., Patel, R.C., Suryaprasad, A., Sanders, K., Moore-Moravian, L., Serrecchia, J., Blankenship, S., Ward, J.W., Holtzman, D. Increases in Hepatitis C Virus Infection Related to Injection Drug Use Among Persons Aged ≤30 Years Kentucky, Tennessee, Virginia, and West Virginia, 2006–2012. MMWR May 8, 2015; 64(17): 453-458.

https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6417a2.htm?s cid=mm6417a2 w. Accessed June 2016.

(3) Surveillance for Viral Hepatitis –United States 2014. Viral Hepatitis Statistics and Surveillance website.

https://www.cdc.gov/hepatitis/statistics/2014surveillance/index.htm. Updated September 22, 2016. Accessed November 2016.

- (4) Achuo-Egbe, Y. N., "Regional Differences of Hepatitis C Virus Infection in Kentucky" (2015). *Theses and Dissertations—Public Health (M.P.H. & Dr.P.H.).* Paper 54. http://uknowledge.uky.edu/cph_etds/54, Accessed January 2017.
- (5) Edlin,B.R., Eckhardt, B.J., Shu, M.A., Holmberg,S.C., Swan,T; Toward a More Accurate Prevalence of Hepatitis C in the United States, 2015, Hepatology Vol 62 (5), November 2015; pp 1353-1363.
- (6) Razavi, H., Elkhourly, A. C., Elbasha, E., Estes, C., Pasini, K., Poynard, T., Kumar, R.; Chronic Hepatitis C (HCV) Disease Burden and Cost in the Untied States; Hepatiology vol 57 (6), June 2013, pp 2164-2170.
- (7) Kentucky Department for Public Health: Know the Facts: Hepatitis C in Kentucky A silent Epidemic in Kentucky. No date
- (8) Koneru, A., Nelson, N., Hariri, S., Canary, L., Sanders, K., Maxwell, J.F., Huang, X., Leake, J.A.D., Ward, J. W., Vellozzi, C. Increased Hepatitis C Virus (HCV) Detection in Women of Childbearing Age and Potential Risk for Vertical Transmission United

States and Kentucky, 2011–2014. <u>MMWR July 22,2016;65(28):705-710</u>. <u>https://www.cdc.gov/mmwr/volumes/65/wr/pdfs/mm6528.pdf</u> accessed July 29, 2016.