At the April 2012 meeting of HepCAP, a brainstorming activity was used to identify ideas for potential coalition projects under five different topics: treatment and care, resource development, awareness, advocacy, and prevention. Please contact Alex Shirreffs at PDPH (Alexandra.shirreffs@pdph.gov or 215-685-6462) if you have other ideas you would like HepCAP to consider.

TREATMENT AND CARE: What ideas do you have to improve linkage to care for people who test positive for HCV?

Major Themes:

- Flexibility and intensive support structures are needed to improve access to care
- Different strategies may need to be applied for insured vs. uninsured clients
- Improve communication between people providing the services to clients (tester, case manager, clinician)
- Providers need resources to better serve their clients – information, knowledge, best practice models

- Continued support for treatment compliance
  - Follow up for dropouts
- Expand number of providers able to provide care
- Limit financial burden to patients
- For uninsured patients
  - Money/financial resources for newly positive patients
    - Lab work upfront and to monitor throughout treatment
- Need to meet patients on their turf
  - Ex: methadone clinics, churches
    - These are sites that might do testing but don’t link to care
- Incarcerated people have a high burden of disease
- Strengthen the relationship/collaboration between providers and testers
  - Formalize their relationship with MOU
  - Case management and the provider system need to work together
- Detailed resource guide for linkage to care
- Guidance for what insurance covers
- Care for the uninsured
- Potential expansion of HIV patient navigators to include HCV care
- Expand central intake for HIV services (hotline) to include HCV services
- Better coordination of PCSI diseases and vaccines
- Educating providers on substance users
- De-stigmatize the HCV test
- Prompt linkage to care (48 hours maximum)
- Walk-in appointments with providers
- Educating providers
  - Starts with the patient
RESOURCE DEVELOPMENT: What resources would you like to see HepCAP develop?

Major Themes:

- A process for hepatitis testing and counseling; counseling messages
- Support for people who are infected
- Access to information about resources through hotline, resource guide, etc
- General and targeted educational materials: providers, risk populations
- Innovative strategies like mobile apps or safe injection kits
- Resources – training, education, etc – to build capacity for clinical and social service providers to serve people living with/at-risk for HCV

- System for testing, which includes linkage to care and counseling
- Develop counseling and testing system that includes training
- Formal training program
- Multiple counseling messages
- Awareness among the community and providers
- Awareness campaign on why people need to know their status
- “Higher level” training module on care
- Ryan White equivalent for HCV, but customized to HCV; case manager serving a different role
- Skype based communication for providers doing HCVV care
  - Direct care more than drugs (labs, liver biopsy, etc)
  - HCV specialists or point person
- Educational materials for patients in a doctor’s office
  - You might not know you have it!
- More focused educational resources for specific groups
  - Linguistic, risk, cultural
  - Youth, safer sex, youth specific language
- Broad and specific campaigns
- If they know someone is positive, awareness, etc
- School system partnerships
- Resource guide for someone who was just diagnosed
- Hotline, walk people through the care system
- Counseling as part of a hotline
- Explaining hep C test results
- Resources specifically for people in corrections
- Additional supportive services like in HIV
- There is a population that is already infected
- Prevention with those who are already infected
- Partnership with methadone clinics
- IOPs
- Prevention of additional infectious diseases, education about HAV/HBV
- Safe injection kits
  - Hopkins kit, plastic card
  - NYC
  - Beyond syringes
- Resources for patients that have been treated, preventing re-infection
- Federal funding for SEPs, greater capacity for more syringe exchange
- Mobile app for resources: contact person, checklist for testing, etc
- Lobbyists
- Limitations on number of providers, expand the number of medical providers
- Materials for providers interested in providing HCV treatment
- PAs and MAs – team system for care
- Financial resources – paying for drugs for uninsured for treatment
- Existence of a best practices guide for new positives, for providers
  - All the services that could be provided
  - Resources, who to call
  - Specialty pharmacies
  - Treatment info guide
AWARENESS: What messages would you want HepCAP to prioritize in an awareness campaign?

Major Themes:

- General and targeted educational messages: providers, risk populations
- Know your status because there is a cure
- De-stigmatize; make it compelling, put a human face on hepatitis C
- Use a variety of media and venues to get the word out

- Existence of the virus
  - Epidemic of
    - Individualize from HIV
  - Number of people who have it/presence by zip code
  - Make the messages personal
  - Ages of people who have it
    - Baby boomers most at risk

- Understanding diagnosis and implications
  - Pathophysiology
    - Effect on the liver
  - “Laissez-faire” attitude among IDUs noted
    - Don’t see care

- Prevention
  - Emphasize for IDUs that ALL works need to be sterile
  - Hep A and B vaccines
  - Difference between different types of hepatitis

- Get tested!
  - Why is testing important?

- Treatment availability and resources if you test positive
  - Better treatment now than in the past
    - Curative
    - Tolerable

- Modes of transmission
  - How is HCV transmitted?
  - not just through IDU
    - Risk factors
    - Age cohort

- Methods for delivering awareness messages:
  - Word of mouth
  - Health Fairs/Street outreach
  - Multi-lingual materials
    - Postcards, simple
    - 3rd grade reading level
  - ID target populations
    - Faith based orgs
  - Products:
    - TV commercials

- De-stigmatization!
  - Around drug use – steer away from abstinence-only messaging
  - Success stories
  - Can’t tell who is positive
  - Targeting YOUTH in messaging
    - Because stigma is associated with how others perceive those infected

- Radio ads
- Banners on lightpoles
- Ads in buses with treatment facilities (health centers, etc)
- Brochures, posters
  - Where were you on ______? You could have gotten HCV

- 70% of people who are infected don’t know
- Recognizing yourself as being at risk
ADVOCACY: What messages about HCV do you think government officials need to hear from HepCAP?

Major Themes:

- Local advocacy is needed – from the state to local districts
- More money put towards hepatitis now means money saved later; cost-savings projections
- Provide specific recommendations for prevention, care and treatment that policymakers can support
- De-stigmatize; make it compelling, put a human face on hepatitis C

- More resources ($$$$$)
- HCV is PREVENTABLE
- Epidemic
- Burden of disease
  - % of those who have hepatitis C and don’t know it
  - Cost of not treating – cost-benefit analysis
- HCV as a regular screening
  - Public health centers could promote testing and care
- Mandatory linkage to care (Ryan White Care Act)
  - What’s the benefit of people knowing their HCV status, if they can’t get treatment?
    - Insurance goes up (pre-existing condition), still no treatment
- Medicaid coverage for treatment and care
  - Part of the essential benefits package
  - Lobby to state
  - Federal incentives
- Government awareness of treatment implications
  - Transportation – hospital to hospital
  - Side effects
  - New Treatment
  - Impact on daily living
- Cost of progression to liver cancer
  - The longer you wait to learn your status, the harder HCV is to treat
- HMO coverage
  - Covered under complete blood workup
- Destigmatizing HCV and drug use
- Have state support the CDC recommendations
  - Birth cohort screenings
  - Screening for non-traditional risk factors
- Lowering the cost of drugs
  - Follow the example of HIV
- Provider incentives to provide treatment (not necessarily monetary!)
  - Why not treat everyone?
  - Alleviate patient fear
  - Diminish provider resistance
  - Address barriers to treatment
    - How intensive treatment is for provider AND patient
      - Time, number of visits
    - Support for patients
      - Fear of losing their jobs because of time commitment and cost
- Community advocacy in every district
  - Medical community needs to get involved to add legitimacy
- Media coverage
  - Cost benefit analysis
  - Human interest
PREVENTION: What ideas do you have to improve HCV prevention efforts?

Major Themes:

- Expand access to safer injection/safer sex/harm reduction resources
- General and targeted prevention messages: providers, risk populations, youth
- De-stigmatize; make it compelling, put a human face on hepatitis C
- Explore treatment as prevention; expand access to testing and HCV treatment/care
- Build on communities: conference for providers, use gatekeepers and peer mentors to push messages out, improve capacity of local harm reduction providers

- Philadelphia safer injection facility
- Education
  - Younger the better
  - Advocacy/support
- Access to safer injection materials/safer sex materials
- Altering drug laws: moving from a criminal to a public health paradigm
- Societal stigma towards populations most affected
- Defining populations at risk and developing specific educational resources
- Stakeholders for different populations
- Reduce incarceration
- Develop culturally appropriate materials
- Increase treatment for drug use
- Educate the general population
- Specific education, targeted
- Define separate populations
- Use technology to speak to some populations
- Find spokespeople – key informants – community gatekeepers
- Provider education: from primary care to other fields
- Treatment education
- Stigma reduction
- Create an infrastructure for hepatitis services
- Alcohol cessation
- HCV Prevention Summit
- Needle exchange
  - Pharmacy expansion
- Messaging targeted to IDUs and those at highest risk for new infections
- Education
- Treatment as prevention
- Defining which populations are at highest risk
- Tailoring education for different populations
- Involving health literacy in messaging
- Peer mentoring
- Stakeholders
- Education about safer injection
- Preventing re-infection
- Safer injection practices/needle use
- Materials for safer sex and safer injection
- Expand the definition of at-risk populations
- Expand/improve screening and testing to prevent new infections
- Disseminate information better to a general population
- Spokespeople to target the message
- Reduce stigma
- Broad educational campaign
- Provider education
- Advocacy to insurers for treatment as prevention