

**Information about the research (Phase 2)**  
**Preventing blood borne virus infection in people who inject drugs in the UK**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. We would like to interview you about injecting and sexual risk behaviours among people who inject drugs and about what kind of intervention you think would be useful and acceptable to reduce blood borne virus risk behaviours that can lead to Hepatitis C, Hepatitis B and HIV. Interventions might include i) information to increase knowledge, ii) to teach skills to enable people to practice safer injecting and sex, and iii) to motivate people to practise safer injecting and sex. The information you provide will be treated confidentially unless you disclose intent to harm yourself or others. One of our team will go through the information sheet with you and answer any questions you have. **Explaining this information sheet to you should take about 5-10 minutes.** Do feel free to talk to others about the study if you wish.

**What is the purpose of the study?**

In the UK, around half of those who inject drugs have been infected with the Hepatitis C virus and around one in every 100 has HIV. Approximately one in six people who inject drugs have ever been infected with the hepatitis B virus. People who inject drugs may be at risk of these blood borne viruses (HIV, Hepatitis C and Hepatitis B) because of sharing injecting equipment (needles and syringes, water, spoons, cotton etc.) and unsafe sex (although the risk of sexual transmission of Hepatitis C is low). These blood borne viruses are preventable and we are looking to work with those at risk to identify ways to achieve this. We are doing this study to learn how best to help people adopt safer injecting and sexual behaviours and work out what kind of intervention (e.g. i) information to increase knowledge, ii) to teach skills to enable people to practice safer injecting and sex, and iii) to motivate people to practise safer injecting and sex) that you would find useful and acceptable.

This study is being conducted in London, Glasgow, Yorkshire and North Wales. This will allow the study to compare the results across different areas in the UK.

## **Why have I been invited?**

People who have injected drugs (other than image or performance enhancing drugs) at least once in the past month are being invited to take part from drug treatment centres, harm reduction services, needle exchanges, sexual health clinics and homeless hostels. We wish to interview a total of 60 people who have recently injected drugs – 15 each from London, Glasgow, Yorkshire and North Wales.

## **Do I have to take part?**

No, it is up to you to decide whether or not you want to take part in the research. If you agree to take part, we will then ask you to sign a consent form. This study is independent of your treatment. You are free to withdraw at any time, without giving a reason. This will not affect the care that you are receiving.

## **What will happen to me if I take part?**

If you decide to take part, you will be interviewed face-to-face by a researcher about risk behaviours among people who inject drugs and about what kind of intervention you think would be useful and acceptable to reduce blood borne virus risk behaviours and increase transmission knowledge. You may refuse to answer some of the questions if you prefer not to. **The interview will take about an hour** and will be audio recorded with your consent. We can interview you today, or we can arrange a time that is suitable for you to be interviewed. You will receive £20 high street gift voucher to cover your time and expenses.

## **Will my taking part in the study be kept confidential?**

Yes. We will follow ethical and legal practice **and all information about you will be handled in confidence**. The questionnaire and audio recording will contain only your study ID (not your name) and will be stored on a secure computer. Once we have done that, the audio recording will be deleted from the recording device. What you say in the interview will be typed out word for word. Only the researchers conducting the study will have access to these typed copies. The researcher will check them to make sure that neither you nor any other person is identifiable from what you have said; any references to names or addresses will be removed. The interviews and the data will be kept on a computer and will be stored separately from

your contact details. Data will be kept securely for 7 years after publication of the findings and then destroyed. Anonymised data (not individual interviews) will be stored with the UK data archive to allow other researchers to use the data in the future. Your data will only be included in the archive if you give your consent to this. If you do not give your permission for your data to be used in this way then it will not be shared.

### **Limitations to confidentiality**

**If you express current or future intention to harm yourself or someone who is specifically identified, there would be no grounds for maintaining confidentiality.** Your key worker or a duty worker at the drug treatment service where the interview has taken place will be told by the researcher of your intentions and the worker will conduct a risk assessment.

### **What are the possible benefits of taking part?**

Whilst there are no immediate benefits to yourself for taking part, this is your chance to use your experiences to help develop an intervention that has the potential to help people protect themselves from blood borne viruses.

### **What are the possible disadvantages and risks of taking part?**

There is low risk of harm by taking part. However, talking about sensitive topics including potential risks for the transmission of blood borne viruses may make you feel worried or anxious. If you are worried or anxious or wish to find out more about blood borne viruses, you will be given the opportunity to speak to a member of staff at a local drug treatment service if you want to. We have also provided you with a range of contact numbers and websites that will be able to help.

### **Contact numbers**

**The Hepatitis C Trust Helpline** [REDACTED] or [REDACTED]  
<http://www.hepctrust.org.uk/> Open 10.30am to 4.30pm Monday to Friday (except

*Bank Holidays and the Christmas break, when dates and times may vary). Helpline is staffed solely by people with hepatitis C, some of whom have been through/or are currently undergoing treatment.*

### **British Liver Trust** [REDACTED]

[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk) (Free helpline, Mon-Fri 09.00-17.00) *The British Liver Trust is the national charity working to reduce the impact of liver disease in the UK through support, information and research.*

### **National Hepatitis Support Line** [REDACTED]

<http://www.hepbpositive.org.uk/> *Help the public and patients overcome hepatitis B. They clarify and reassure patients that hepatitis b is both easy to vaccinate against and caught early on an easy to manage common child acquired condition.*

### **National Sexual Health Line** [REDACTED] (24 hours)

*The National Sexual Health Line is UK-wide and provides confidential advice and information on all aspects of HIV, AIDS and sexual health. The Helpline can also provide UK wide referrals to specialist services. Open 24 hours a day, seven days a week. All calls are taken by trained and paid staff. It is not a counselling service, but gives you details of local helplines & services if needed.*

### **Terrence Higgins Trust Direct Helpline** [REDACTED]

*(open 10am - 10pm Monday - Friday, and 12 noon - 6pm on Saturday and Sunday). Terrence Higgins Trust Direct Helpline can give you HIV information, advice and support over the phone.*

### **Local services**

#### **Burrell Street Sexual Health Clinic, 4-6 Burrell Street, London** [REDACTED]

*Burrell Street offers tests and treatment for all sexually transmitted infections. Burrell Street has a sexual health counselling service which provides risk reduction interventions, sexual health advice, and an opportunity to discuss your relationships, sexual identity and concerns regarding your drug and alcohol use.*

#### **Community Drugs and Alcohol Service, 151 Blackfriars Road, London**

[REDACTED] *This service provides assessment, treatment and advice for people, aged over 18, who have substance misuse (drug and/or alcohol) related problems.*

### **What will happen to the results of the research study?**

What you say will be used to help develop an intervention to reduce risky drug use and sexual practices among people who inject drugs. We intend to publish the results at the end of the study. A summary of the results will also be available on the project website

<http://www.kcl.ac.uk/ioppn/depts/addictions/research/drugs/bloodborneviruses.aspx>

and a brief summary of the results will be available in June at the services where the

research took place. It is possible that we would include your actual words in quotations in the report but we would not use your real name so that people will not be able to identify you in any report/publication.

### **Who is organising and funding the research?**

The research is being led by Dr Gail Gilchrist, from the National Addiction Centre at King's College London, and is funded by the National Institute for Health Research. This study is being conducted in London, Yorkshire, Glasgow and North Wales. If you wish to talk to someone about the research please contact Dr Davina Swan on [telephone number].

### **Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by NRES Committee South East Coast - Brighton & Sussex (Reference: 15/LO/0387).

## Contact details

If you agree to take part in the research, we will arrange a time to meet with you again in the next couple of weeks. We can make this before or after your next visit to this service if that suits. We will contact you to remind you of the time we arrange today and also to check if you still wish to take part in the study.

***Please can you fill out your contact details so that we can stay in touch.  
Thanks!***

Name: \_\_\_\_\_

Mobile telephone number: \_\_\_\_\_

Home telephone number: \_\_\_\_\_

Email address: \_\_\_\_\_

## **CONSENT FORM (Phase 2)**

**Title of Project: Preventing blood borne virus infection in people who inject drugs in the UK**

**Name of Researcher: Dr Gail Gilchrist**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 12/03/15 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected.
  
3. I understand the limitations to confidentiality.
  
4. I understand the interview will be audio recorded.
  
5. I understand that the data will be published at the end of the study and that completely anonymous quotations from the interview may be used in the report/publication.
  
6. I agree to my anonymous interview data being shared with researchers at the four institutions where the research is being carried out – King’s College London, University of the West of Scotland, University of York and NHS Wales.
  
7. I agree to take part in the study

***Please initial the following box if you agree with the following statement. Your participation in this research study will not be affected if you do not agree with this statement***

8. I agree to my anonymous interview data being stored with the UK data archive

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature