

**Experiences of Accessing Post Exposure Prophylaxis**  
CHAPS Basic Research Project - Sigma Research  
Telephone Questionnaire

Interviewer Initials: \_\_\_\_\_ ID Number: \_\_\_\_\_

Date of Interview: \_\_\_\_\_

**SECTION ONE: INTRODUCTION**

I just want to give you an idea about this research, and the kinds of questions I will be asking you over the next half hour or so. This project is about how and why people have requested PEP treatment, and what their experiences have been along the way. I want to be able to keep the interview as brief as it needs to be, so for this reason I may get you to focus your answers a bit in some instances. You may find it hard to remember all of the details that I will ask you about, but we just ask that you recall as much as you can, and you may remember more as the interview goes on.

The interview will start with questions about the specific incident that led you to request PEP treatment (and if this has happened more than once, I will be asking about the most recent time). Then I will ask questions about how you found out about PEP, and what specific steps you took in order to request it on that occasion, and what your evaluation of that whole process was. If you did end up taking PEP treatment, I will ask about how that went, and what pills you were prescribed. Finally, I will ask a few questions about how your experience in relation to PEP may or may not have impacted what you might do in the future. Does that all sound ok? \_\_\_\_\_

Also, I will need to tape record this interview over the phone. The tape will be transcribed, and later destroyed, so there is no record of your voice, and no way that you can be individually identified in any of our research. Is that all right with you? \_\_\_\_\_

1.0 Have you tried to access PEP on more than one occasion?

☐ No - just one time      How long ago was that? \_\_\_\_\_

☐ Yes - more than once      Please tell me how long ago each of those times were: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**SECTION TWO: EXPOSURE INCIDENT**

All the questions that I am going to ask you in this first section of the interview will relate to the most recent time that you tried to access PEP, so even if you have thought about it, tried to get it or taken it on prior occasions, all of these questions will relate only to the last time that you looked into taking PEP.

2.0 On that occasion, can you briefly tell me why you considered accessing PEP?

☐ Sexual exposure → GO TO SECTION 2.1 BELOW

☐ Intravenous drug injecting → GO TO SECTION 2.2 **PAGE 3**

☐ Other      What: \_\_\_\_\_ → GO TO SECTION 2.2 **PAGE 3**

## 2.1 Sexual Exposure Incident

2.1.1 Was your sexual partner:

- ☐ Regular
- ☐ Casual

2.1.2 Where did the sex take place?

- ☐ Your home
- ☐ Sexual partner's home
- ☐ Sauna
- ☐ Cruising Ground / Cottage
- ☐ Sex Club / Bar
- ☐ Other Where: \_\_\_\_\_

2.1.3 What kind of sex did you have on that occasion?  
(Circle as appropriate)

### Anal intercourse

receptive

insertive

condom failure: \_\_\_\_\_

no condom

cum

no cum

### Oral

receptive

insertive

condom failure: \_\_\_\_\_

no condom

cum

no cum

Other: What: \_\_\_\_\_

2.1.4 Do you know the HIV status of the sexual partner with whom this incident occurred?

- ☐ They are definitely positive  
When did you know this? (*Before/after sexual exposure*)  
\_\_\_\_\_
- ☐ They might be positive  
What makes you think so?  
\_\_\_\_\_
- ☐ Don't know  
\_\_\_\_\_

2.1.5 Has that type of situation happened to you more than once?

\_\_\_\_\_

Thinking about this most recent situation, can you tell me how it was different to other occasions?

GO TO SECTION 2.3 'Considering and Accessing PEP' → **PAGE 4**

## 2.2 IDU/Other Exposure Incident

I would like to ask you about what happened in relation to the one, or the most recent HIV risk incident that led you to seek out PEP.

**AND if IDU, be sure to include:**

*Regular/unknown injecting buddies?*

*Where did injection take place?*

*Any risk reduction strategies taken? Bleaching/washing? Order of injecting?*

*Known HIV status of other injectors?*

*Did something different happen at that time to make you consider PEP?*

GO TO SECTION 3 'Considering and Accessing PEP' → **NEXT PAGE**

### **SECTION 3 CONSIDERING AND ACCESSING INFORMATION ON PEP**

#### **3.1 Knowing about PEP**

- 3.1.1 RECAP: So we have talked about the fact that you felt concerned about exposure to HIV when you (*had type of sex / injected / other*) at (*place*) with a (*casual/regular partner OR other*).

You have also said that you were (*certain/uncertain*) of that person's HIV positive status.

- 3.1.2 Do you recall at what point you began to think about taking PEP as a direct result of that incident with that person? Tell me a bit about that.

*Prompts:        at the time? Later?*  
*Self-talk, revelation from partner/others?*

- 3.1.3 How long before this time had you first heard of PEP?

\_\_\_\_\_

*Was it well before this incident or at the time it occurred?*

- 3.1.4 How did you know about PEP?

- ☐ gay press
- ☐ posters in gay scene
- ☐ mainstream press
- ☐ online
- ☐ friend
- ☐ health professional
- ☐ sexual / injecting partner at time of incident
- ☐ other: who/what? \_\_\_\_\_
- ☐ not sure

### 3.2 Accessing PEP

- 3.2.1 Now I want to step through with you your recollection of the ACTIONS you took leading up to going and asking for PEP. Before I go through all those steps, can you tell me where you ended up going to ask for it?

\_\_\_\_\_

\_\_\_\_\_ (can you tell me what hospital or  
at least what city or town that was in?)

- 3.2.2 Thinking now about the ACTIONS you took following on from that incident you have just described..and your possible desire to seek out PEP.

What was the first thing you actively did?

*If information: online or paper - where/risk assessment?/referral?/any good?  
If person: who/why/any good? / stigma?/ empathy?/knowledge?*

*Stop short of triage/face to face risk assessment/dispensing medicine, as that is in following section....*

What was the next thing you did?

*If information: online or paper - where/risk assessment?/referral?/any good?  
If person: who/why/any good? / stigma?/ empathy?/knowledge?*

*Stop short of triage/face to face risk assessment/dispensing medicine, as that is in following section....*

What was the next thing you did?

*If information: online or paper - where/risk assessment?/referral?/any good?  
If person: who/why/any good? / stigma?/ empathy?/knowledge?*

*Stop short of triage/face to face risk assessment/dispensing medicine, as that is in following section....*

- 3.2.3 What was the time gap between the time you started thinking about PEP, and the time you actively went to seek it out?  
\_\_\_\_\_ hours \_\_\_\_\_ days \_\_\_\_\_ months

### **3.3 Accessing PEP - protocol, dispensing, testing, consent**

- 3.3.1 Where did you eventually go to get access to PEP?

- ☐ GU Clinic/Sexual Health Clinic  
☐ A&E Department  
☐ HIV Clinic  
☐ Other: Where? \_\_\_\_\_

#### ***\*Frame all remaining questions in this section in relation to this response***

- 3.3.2 From the time you arrived at (*clinic/A&E/other*) about how long was the wait before you were seen?  
\_\_\_\_\_

- 3.3.3 How much privacy did you have when you first arrived and needed to explain why you were there?  
\_\_\_\_\_

- 3.3.4 Once you got there, did any one ask in more detail about your (*sexual/injecting/other*) history in relation to HIV risk?

- ☐ No  
☐ Yes Who? \_\_\_\_\_

- 3.3.5 Did anyone go through with you in detail about the risk incident that you described to me at the start of this interview?

- ☐ No  
☐ Yes Who? \_\_\_\_\_

- 3.3.6 Did you take an HIV test?

- ☐ No  
☐ Not sure  
☐ Yes A) Who suggested it? \_\_\_\_\_ (*you/other*)  
B) Did they explain to you why you would have to take the test?

\_\_\_\_\_ C) How long did you have to wait for the result?

\_\_\_\_\_ *one hour/next day/next week?*

3.3.7 Following on from your initial assessment, what was it recommended that you do?

- ☐ Consider taking PEP
- ☐ Not take PEP because risk of exposure was not judged to be high
- ☐ Not take PEP for another reason: What? \_\_\_\_\_
- ☐ Other: What? \_\_\_\_\_

Did you agree with and feel comfortable with that recommendation? Why/Why not?

\_\_\_\_\_

\_\_\_\_\_

**\*\*\*Ask A&E attendees only the following questions\*\***

for others, continue BELOW THE BOX

3.3.8

A) *(If HIV tested)* Where did you take that HIV test?

- ☐ In the A&E department
- ☐ At GU in same hospital
- ☐ Other place in same hospital: Where? \_\_\_\_\_
- ☐ Other: Where? \_\_\_\_\_

B) Do you know if the A&E staff consulted with other staff from the GU / or Infectious Disease or other departments at any time during your visit?

- ☐ Don't know
- ☐ Doctor: What? \_\_\_\_\_
- ☐ Nurse: What? \_\_\_\_\_
- ☐ Health Advisor: What? \_\_\_\_\_
- ☐ Other: What? \_\_\_\_\_

IF PEP **NOT** RECOMMENDED GO TO 3.3.9 → **NEXT PAGE**

IF PEP **WAS** RECOMMENDED GO TO 3.3.10 → **NEXT PAGE**



3.3.9 After the point that it was recommended that you did not receive PEP on that occasion, what did you do next?

*Went home/nothing further?*  
*Attempted access elsewhere? Elicit narrative and step through prior questions.*  
*Would you try to access PEP again in future?*

**\*\*\*GO TO SECTION 3.4 - page 10 FOR NON-RECIPIENTS\*\*\***

3.3.10 Were you warned in advance about the possibility of adverse reactions to the drugs?

- ☐ No → GO TO 3.4 **NEXT PAGE**  
☐ Yes

3.3.11 Which of the following side effects do you remember them mentioning beforehand?

- ☐ Nausea  
☐ Vomiting  
☐ Diarrhoea  
☐ Fatigue  
☐ Rash  
☐ Liver function decline  
☐ erectile dysfunction  
☐ lipodystrophy  
☐ Other: What? \_\_\_\_\_

3.3.12 Did they advise what you could do to minimise the effects?

- ☐ No  
☐ Don't recall  
☐ Yes: What? \_\_\_\_\_  
(Medical/non medical interventions?)

3.3.13 Did they discuss with you some other possible difficulties with staying on the full course of PEP?

- ☐ No  
☐ Don't recall  
☐ Yes: What? \_\_\_\_\_

### 3.4 Quality of Advice and Access

- 3.4.1 How confident did you feel about the health professionals you saw in terms of their ability of to deal with your questions about PEP and to evaluate your situation?

*other comments? consulting with other staff/sources required?*

- 3.4.2 Overall how satisfied were you with the way in which your request for PEP was handled?

- ☐ Very satisfied  
☐ Quite satisfied  
☐ Satisfied  
☐ Not very satisfied  
☐ Not at all satisfied

*(If less than satisfactory)* If you were unhappy with the process at any point, what steps did you take (if any) to make this known?

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**\*\*\*FOR NON - RECIPIENTS - NOW GO TO SECTION FIVE, PG 16\*\*\*\*\***

- 3.4.3 Were you given you enough information to feel safe in choosing to take PEP?

- ☐ Yes: Why do you say that?

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- ☐ No: What could have been done better?

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- 3.4.4 Were you given any literature about PEP to take home and read at a later date if necessary?

- ☐ Yes  
☐ No  
☐ Don't recall

## Section 4 - Receiving PEP treatment

### 4.1 Dispensing PEP

4.1.1 How long was it between the HIV exposure incident that you described, and the time that you received your first dose of PEP medication?

\_\_\_\_\_ hours \_\_\_\_\_ days

4.1.2 How long was it between the time you arrived at (*GU/A&E/other*), and the time that you received your first dose of PEP medication?

\_\_\_\_\_ hours \_\_\_\_\_ days

4.1.3 Did you receive any pills there and then at the (*A&E/GU clinic/other*) to start you off?

- ☐ Yes
- ☐ No

4.1.4 Did you take that first dose before or after receiving an HIV test result?

- ☐ before
- ☐ after
- ☐ not sure

4.1.5 When you were given the full prescription for the course of PEP, did you know where to get it filled?

- ☐ Yes: Where? \_\_\_\_\_
- ☐ No

4.1.6 Which drugs did you take?  
(Tick as many as apply)

NRTIs (known as 'nukes')

- |                              |  |   |
|------------------------------|--|---|
| <input type="checkbox"/> AZT | <input type="checkbox"/> abacavir                      | <input type="checkbox"/> stavudine                      |
| <input type="checkbox"/> 3TC | <input type="checkbox"/> emtricitabine                 | <input type="checkbox"/> <i>Trisivir</i> <sup>TM</sup>  |
| <input type="checkbox"/> D4T | <input type="checkbox"/> <i>Emtriva</i> <sup>TM</sup>  | <input type="checkbox"/> <i>Videx</i> <sup>TM</sup>     |
| <input type="checkbox"/> ddC | <input type="checkbox"/> <i>Epivir</i> <sup>TM</sup>   | <input type="checkbox"/> zalcitabine                    |
| <input type="checkbox"/> ddI | <input type="checkbox"/> <i>Combivir</i> <sup>TM</sup> | <input type="checkbox"/> <i>Zerit</i> <sup>TM</sup>     |
| <input type="checkbox"/> FTC | <input type="checkbox"/> didanosine                    | <input type="checkbox"/> <i>Zerit PRC</i> <sup>TM</sup> |
|                              | <input type="checkbox"/> lamivudine                    | <input type="checkbox"/> <i>Ziagen</i> <sup>TM</sup>    |
|                              | <input type="checkbox"/> <i>Retrovir</i> <sup>TM</sup> | <input type="checkbox"/> zidovudine                     |

NNRTIs (known as 'non-nukes')

- ☐ efavirenz  
☐ nevirapine  
☐ *Sustiva* <sup>TM</sup>  
☐ *Viramune* <sup>TM</sup>

NtRTIs

- ☐ tenofovir  
☐ *Viread* <sup>TM</sup>

PIs

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> amprenavir                     | <input type="checkbox"/> indinavir                     | <input type="checkbox"/> <i>Reyataz</i> <sup>TM</sup>  |
| <input type="checkbox"/> <i>Agenerase</i> <sup>TM</sup> | <input type="checkbox"/> <i>Invirase</i> <sup>TM</sup> | <input type="checkbox"/> ritonavir                     |
| <input type="checkbox"/> atazanavir                     | <input type="checkbox"/> <i>Kaletra</i> <sup>TM</sup>  | <input type="checkbox"/> saquinavir                    |
| <input type="checkbox"/> <i>Crixivan</i> <sup>TM</sup>  | <input type="checkbox"/> lopinavir                     | <input type="checkbox"/> <i>Telzir</i> <sup>TM</sup>   |
| <input type="checkbox"/> <i>Fortovase</i> <sup>TM</sup> | <input type="checkbox"/> nelfinavir                    | <input type="checkbox"/> <i>Viracept</i> <sup>TM</sup> |
| <input type="checkbox"/> fosamprenavir                  | <input type="checkbox"/> <i>Norvir</i> <sup>TM</sup>   |  |

Fusion inhibitors

- ☐ T-20  
☐ enfuvirtide  
☐ *Fuzeon* <sup>TM</sup>

- ☐ Others: Which? \_\_\_\_\_  
☐ Not sure

4.1.7 How was the decision made about which drugs you should take?

*Self/other?*  
*History of source?*

4.1.8 Which (if any) of the following side effects did you experience while taking PEP?

- ☐ None
- ☐ Nausea
- ☐ Vomiting
- ☐ Diarrhoea
- ☐ Fatigue
- ☐ Rash
- ☐ Liver function decline
- ☐ erectile dysfunction
- ☐ lipodystrophy
- ☐ Other: What? \_\_\_\_\_

At what point did they occur? How did you manage it?

*How long did they last? Did they stop after the course of treatment? If so, how much later?*

## 4.2 Personal and social effects of taking PEP

4.2.1 Did you miss any doses?

- ☐ No  
☐ Yes: How many? \_\_\_\_\_

Did you know what to do? \_\_\_\_\_

4.2.2 Did you finish the course of PEP to the end?

- ☐ Still taking it now  
☐ Did complete  
☐ Did not complete: Why not? \_\_\_\_\_

4.2.3 Do you remember being offered any ongoing support or advice to help you stay on your treatment?

- ☐ Not sure  
☐ No  
☐ Yes: What? \_\_\_\_\_

Did you take it up? \_\_\_\_\_

Any use? \_\_\_\_\_

4.2.4 (*if not still on it*) How long ago did you finish that course of PEP?

\_\_\_\_\_ days \_\_\_\_\_ months \_\_\_\_\_ years

4.2.5 Did you have to take time off (*work/school/other*) responsibilities because you were taking PEP?

- ☐ No  
☐ Yes: How long/why? \_\_\_\_\_  
(*impact?*)

4.2.6 (*if applicable*) Did you tell your (*employer/college/other*) that you were taking PEP? *Why/why not? How did that go?*

4.2.7 I am now going to ask you about others that you may or may not have told about taking PEP.

- ☐ No one
- ☐ Regular/Primary sexual partner
- ☐ GP

For each of these following categories, please give me a proportion of those people who you did tell, and whether that was mainly during or after you took the treatment.

Family	<input type="checkbox"/> All	<input type="checkbox"/> Some	<input type="checkbox"/> None
Friends	<input type="checkbox"/> All	<input type="checkbox"/> Some	<input type="checkbox"/> None
Co-workers	<input type="checkbox"/> All	<input type="checkbox"/> Some	<input type="checkbox"/> None

Others? \_\_\_\_\_

4.2.8 Have you had any follow up consultations since taking PEP?

- ☐ No
- ☐ Yes: When?
  - ☐ Four weeks
  - ☐ Three months
  - ☐ Six months
  - ☐ Other: What? \_\_\_\_\_

Where:

\_\_\_\_\_

Did they provide follow up HIV tests at these consultations?  
(If yes, which visits/ \_\_\_\_\_  
what result?) \_\_\_\_\_

## **SECTION 5 FUTURE RISK**

5.1 Do you currently know your HIV status?

- ☐ No  
☐ Yes    Status: \_\_\_\_\_  
Date of most recent Test: \_\_\_\_\_

5.2 (*only ask if HIV negative*) If a future risk incident occurred how likely would you be to request PEP again?

- ☐ Definitely would try to access PEP again.  
☐ Would consider  
☐ Would not try to access PEP again.

Why/Why not? \_\_\_\_\_

5.3 Do you think the experiences you described to have had any kind of impact on your actions that relate to HIV risk?

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5.4 Since the incident you described, have you had any subsequent (*sexual/ drug injecting / other*) risks that could have exposed you or others to HIV? (*if yes - was it during/after taking or accessing PEP what did they do about it?*)

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That is the end of my questions for you. Was there anything further that you wanted to add or to ask me before we finish?

We will send out an email in about six months time when the report is completed, is that something that will interest you? It will be freely available either in hard copy or on the web.