Community Engagement Meetings Report

Lessons learned from the HEPscreen pilot studies
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**Work Package 5 Report**

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*Prepared by:*

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**Disclaimer**

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1 Introduction

As part of HEPscreen Work Package 5, dealing with communication to the target groups, meetings with the target groups of the pilot studies were held. The primary aim of these Community Engagement Meetings (CEM) was to get feedback from the communities that were expected to be reached by the HEPscreen pilot interventions.

The CEM were held in three of the four pilot sites, namely in Budapest, London and Barcelona. The meetings are facilitated discussions (focus groups) with 8-10 people. The topics that were discussed differ according to the design of the screening pilots in each area.

The methodology and findings of the CEM are described in separate chapters for the three sites. The meetings in London and Barcelona were organised and analysed by staff involved in the HEPscreen project and with expertise in qualitative research. The meetings in Budapest were organised by the external evaluators of the project who were based in Budapest and had expertise in qualitative research.
2 Local community engagement in Budapest – focus group report

Prepared by Ferenc Marvanykovi and Gergely Horváth

2.1 Executive Summary of the main findings

The participants found the screening method – attaching the HCV screening to the obligatory HBV screening at the 12th week of pregnancy – adequate and comfortable as there was no extra effort on sample taking.

The participants trusted and cooperated with the child health visitor, thus we judge it a valuable approach to involve them in the screening. The participants reported no negative attitudes from the staff involved during the preliminary counselling or in the follow-up process.

The participants found it important for themselves and their community to take part in a screening like this.

The participants agreed with the aims of the screening and would recommend it to others or would take part again in a similar project, so they were satisfied with its delivery in general.

Some minor recommendations:

As Chinese migrants tend to change residence within Budapest under or after pregnancy, regionally responsible child health visitors may have difficulties following up the participants. It is difficult to find an ultimate solution to this problem. Health Visitors could use subjects’ personal network to find them at their new location.

HBV sample taking is obligatory and samples are taken to the National Center for Epidemiology (NCE) by the law. However, not all the samples arrived at the NCE, that meant some losses in case numbers. Thus, sending the HCV samples to the NCE did not result HBV and HCV samples interlinked (and personalised) in all the cases at the NCE. This situation and process should be revised.

More emphasis may be given to the first, preliminary information session by the child health visitors about the hepatitis infections, vaccination and treatment options.

It should be well-defined when and how the participants are informed about their screening results.

Besides the translation of a short information sheet on hepatitis and the project aims that was also part of the documentation of attaining informed consent, we identified no tool that was tailored to the special needs of the migrants participating.
Involving community based approaches (using relevant locations, key persons, outreach methods) would contribute to recruit hard-to-reach groups as well.

The participants did not know much about the hepatitis infections in general before the screening opportunity and we felt uncertainties after the screening as well. The screening opportunity may be strengthened by more information provision.

2.2 Introduction

Two focus group sessions were held to obtain feedback from Hepscreen project participant about their impressions about the project aims and delivery of services during the project from the child health visitors.

One focus group session was organised for the Hungarian speaking migrants, another for the Chinese migrants as these two groups were identified relevant as larger communities in Hungary.

The two sessions were held by two researcher of the RIDS team, Ferenc Márványkövi and Gergely Horváth as amendment of their contract of evaluating the Hepscreen project. The focus group meetings followed an adopted version of the guidelines that were elaborated for the participants in Barcelona under the project.

General Aim:
The general aim was to know the perception about the pregnancy screening from women who completed their participation in hepatitis screening of the Hepscreen project and possible proposals for improving future interventions.

Background information
The local project that took place in two districts of Budapest and in Pest county aimed to reach a total of 500 pregnant migrant women, particularly aiming to reach pregnant women in their 16th week of their pregnancy from China, Vietnam, Romania and countries of former Yugoslavia. The pilot project was launched on 1 April 2013 was completed in May 2014.

Study participants were approached by local and regional child health visitors who informed pregnant women about the possibility of HBV and HCV screening. At the first counselling session, where subjects were informed about the possibility of the screening, a 15-minute Hepscreen mini-interview was also recorded. Once the study participant agreed, she signed the written consent form and then she was offered a free-of-charge counselling. Then subjects attended a gynaecologist for serology sample taking for the obligatory HBV screening. This took place either in private clinics or in outpatient centres or at the National Centre for Epidemiology (NCE). Blood test was free of charge. As NCE acted as the only assigned centre for laboratory analysis in the process of pregnant HBV screening, all samples from all doctors (private or public) ended up at the NCE. Samples were collected at NCE laboratory for viral hepatitis and tested for HBV (obligatory for all) and HCV (Hepscreen participants only). Informed consent clients (study participants’) data were linked to their blood samples at the NCE, tested also for HCV. Laboratory tests for HBV took a total of 48 hours to complete, while HCV tests took longer as consent from subjects was required.
HCV results were sent exclusively to the patient. Results of HBV tests were sent to the gynaecologist who referred subjects to testing, professional epidemiology staff and patients. It is patients that showed the results to child health visitors. Medical doctors informed subjects about positive results who was then informed by the health visitor about treatment options: child health visitors provided subjects with information material and flyers written in their own language. Health visitors were allowed to offer but could force subjects to undergo treatment. HBV positive cases were referred to the specialised hospital for infections (Szent László Hospital) where anti-viral vaccination was provided for positive cases and their family members. Further treatment was also offered at the hospital.

Two focus group discussions, where selected study participants were involved, were held in Budapest in June and July 2014 in order to achieve the general aim of the local community meetings (for methodological details, please see next section). Discussion were held at local outpatient centres, led by the external evaluators of the Hepscreen project.

2.3 Methods

Date, time, location and length of the focus group sessions

I. Romanian migrant group speaking Hungarian as native language. These subjects migrated from the Transylvanian part of Romania where Hungarian is also spoken. All interviews spoke fluent Hungarian so the focus group discussion was held in Hungarian. (HU-MIG)
   5 June 2014, 10:00-11:00,
   10th district, 1105 Budapest Újhegy sétány 13-15

II. For Chinese mothers (CHI-MIG)
    9 July 2014, 10:00-11:00
    10th district. Kőrösi Csoma Sándor út 43-51.

Recruitment process (sampling)

- Inclusion criteria: participants in the pregnancy screening that went through the whole process (from contact with the child health visitor, to laboratory result, to possible vaccination of the baby or parents). No referral to antiviral treatment was identified among the participants.
- Recruitment took place via telephone calls.

Focus group participants

- In the HU-MIG group 7 mothers participated.
- In the CHI-MIG group 3 mothers participated.
- Incentive: food vouchers (amount: cc. 33 euros).

Process and methods

- Discussions were guided by a two moderators, one acting as a catalyst in the discussion
the other acting as observer and note-taker. The sessions were accompanied by one community health visitor, who contributed to the organisation and logistics of the meetings and was in charge of the incentives.
- Meeting time frame was 90 minutes with coffee break at the end of the session.
- For the session with Chinese mothers an interpreter was present but the Hungarian session.
- Sessions were held in a convenient place for participants, where they use child care in general.
- Aims of the meetings, general rules (confidentiality) were presented at the start of the sessions.
- In the first part participants commented on and discussed the different issues related to the specific aims of the HepScreen project.
- In the second part the moderator asked the participants to rate different statements about the aims and process of the project in writing (short questionnaire is presented in the annex).
- At the end participants discussed any further questions about viral hepatitis and treatment options.
- Some socio-demographic data were recorded (age, sex, ethnicity, place of birth, duration of stay in Hungary) on the short questionnaire in writing but anonymously.
- Feedback and closing
- Audio recording of the sessions took place with informed consent of the participants.

Focus group guide
The standardised focus group guide, which was modified according to the context of the Hungarian pilot site, included the following main sections.
1) To explore aspects related to the counselling (visit) of the local and regional child health visitor.
2) To explore the perception about accessibility to participate in the different phases of the study.
3) To explore aspects related to the health care received (serology sample taking, treatment).
4) To explore the perception on aspects related to the hepatitis (risks, fears, care, etc.).
5) To explore proposals for implementation of screening system for migrant population.

Attitude statements sheet (voting stickers)
On the attitude statement sheet, respondents were invited to rate the different issues of the pilot project on a scale from 1 (minimum rate) to 5 (maximum rate). There were a total of 20 statements listed in four sections:
1) Counselling meeting with the child health visitor
2) Results
3) Staff

4) Screening programme / study in general

The sheet took 5-10 minutes to complete. Participants were also invited to provide their age, country of origin and the length of they stay in Hungary.

2.4 Results

2.4.1 Specific aim: to explore aspects related to the counselling (visit) of the local and regional child health visitor (CHV)

HU-MIG group
Subjects went to see CHWs who were informed about the screening (blood test would be taken once to screen for HCV and HBV). Out of 7 subjects 2 mentioned that CHV did not talk about HCV at the consultation. 3 subjects said they had already knew what HCV was. Information material was easy to understand. Letter of consent signed at the end of the session.

Subjects emphasised that the level of knowledge about HCV does not depend on where you come from but whether you have already been affected in any way (either yourself or someone around you).

Subjects were glad to be screened for both viruses, they thought that it was very useful. No negative feelings expressed about the counselling session with the CHV.
Respondents mentioned that they had not been informed about what to do if someone had been found positive.

It was not clarified either why they had been chosen for HCV screening.

CHI-MIG group
Chinese participants mentioned that they heard a lot about the consequences of hepatitis infection, thus appreciated the opportunity to get tested for HCV together with the obligatory HBV screening for pregnant women.

They also expressed that their preliminary knowledge was not adequate about the HCV.

They appreciated the Chinese information sheet about the HCV as it was easy to understand, it would have not been understandable in Hungarian. They did not keep the sheet though.

2.4.2 Specific aim: to explore the perception about accessibility to participate in the different phases of the study

HU-MIG group
Too much waiting time for blood test to be taken in state hospitals / outpatient centres.
CHVs told subjects where to get tested.

Blood test was confirmed by subjects to CHVs so CHVs could verbally monitor completion of blood tests. CHVs also had subjects fill out a questionnaire that subjects did not remember clearly but there were no negative feelings expressed about this questionnaire. CHVs also informed subjects that their blood sample had been sent for analysis. Subjects found these information useful.

To get an appointment: easy both in private and state outpatient centres, but too much waiting time in state ones.

No negative feelings about getting tested but subjects expressed a bit of an uncertainty why migrants had to be tested (slight discrimination felt here) : migrants carry viruses? CHVs dismissed uncertainties.

**CHI-MIG group**
Participants expressed no negative attitudes to get tested and appreciated the opportunity but found hard to follow the examinations.

Foreign language is a difficulty. Generally a Chinese mate who speaks Hungarian accompanies the client in the health care system, but if not present, the process may block.

Chinese participants are reluctant to take part in medical examinations in the first three months of pregnancy.

**2.4.3 Specific aim: to explore aspects related to the health care received (serology sample taking, treatment)**

**HU-MIG group**
State hospitals had not been informed about the project / screening, nurses and doctors were a bit reluctant first to do the test, they seemed unprepared but did the test eventually. Doctors felt that the sample taking is an unnecessary must. Private care was very flexible about HCV screening.

Subjects were explained by CHVs what happens right after the serology sample taking – where it will be sent to and why.

Results were sent to subjects by regular mail – CHVs asked subjects if they had received the results. If one of them had been found positive, they would have turned to CHVs not the doctor because doctors did not seem trustworthy.

**CHI-MIG group**
Chinese participants explained that the gynaecologists did not know about the project, that was not a hindrance just one participant reported surprise from the doctor. They also expressed that there are “so many examinations” that they found it difficult to follow what samples were taken and where to expect the results.
They also expressed that the doctors and medical staff have high prestige so what they recommend to participate in, they would agree to do so.

They were uncertain where to get the results from. As they got no alerting indication they were calm without asking for the result proactively.

2.4.4 Specific aim: to explore the perception on aspects related to the hepatitis (risks, fears, care, etc.)

HU-MIG group
Participants did not report any fear when hearing about HCV. They did not even fear what happens if they had been found positive. As CVHs explained it is very useful and important, they held no negative feelings.

They expressed certain ambiguity about why migrants were selected for the project, they felt a bit of a discrimination. These feelings were not shared with anyone.

Subjects do not consider themselves as a community, they do not stick together, therefore they could not judge if this target group is at risk regarding HCV and HBV. For the same reason, other issues such as level of awareness in the community or discussing these issues with community members were irrelevant for them.

CHI-MIG group
For these participants health of the child is of crucial importance.

Participants did not meet any stigma or negative attitudes during the projects form the CHVs or medical doctors.

2.4.5 Specific aim: to explore proposals for implementation of screening system for migrant population.

HU-MIG group
Participants consider the initiative (screening programme) very useful, especially conducting it in special target groups, however, every pregnant woman should be screen for both HCV and HBV regardless of the fact whether they are migrants or not. HCV screening should be free to all.

It was proposed that HBV and HCV screening should be offered together, being more comfortable for the clients (less efforts, eg. one appointment with the doctor, less stressful, one travelling etc.). If this was plausible, they would definitely recommend it to others as well.

It was also proposed that it should be more emphasised and better explained why migrants are screened.
All actors of the screening programme (nurses, CHVs, doctors, gynaecologists, etc.) should have been equally informed about the project – information was not shared properly.

Subjects also mentioned that if someone had been found positive, all her family members should be screened too.

There were two issues that were particularly liked by the participants: screening was free and CVHs were well-prepared and convincing. CVHs are the most valid subjects to inform clients about viruses (not other actors such as doctors, municipality, etc.). The best method is the personal contact with CVHs.

**CHI-MIG group**

Chinese participants found important for their community to get tested for hepatitis, as it is a hot topic for their home country too.

They would recommend other community members to participate in a project like this.

One of them reported that hepatitis screening is important for the gravidas, but of lesser important for the others (general migrant population).

They felt open and free to discuss the risks and infections among their community, reported no stigma or other barriers incl. cultural, gender, religious or other barriers.

Participants accepted “western medicine” and were willing to accept screening or treatment in the health system of Hungary.

They also expressed that if they have no social security, it is a question of money only to get examined and tested.

**Feedback on the basis of the ‘voting stickers’**

The two sessions were accompanied with a short questionnaire using 5-scale Likert scales about aspect relating to the aims of the project.

All participants answered these questionnaires anonymously. That is 7 questionnaires in Hungarian and 3 in Chinese, as these were translated for their comfort.

Due to the low case numbers, the questionnaires were not analysed statistically, but looked through thoroughly and those points (statements) were collected, where some problems – lower ratings – occurred in some occasions.

**HU-MIG group**

In general, the participants were satisfied with the staff (child health visitors) involved in the project, they experienced no stigma or any other negative attitudes. They agreed with the screening option and find it a comfortable way to get tested for HCV as the blood samples were taken for HBV anyway. They would recommend it to others to take part in a similar project.
Members of the Romanian migrant group recognised no special cultural needs that should have been taken into account during the screening.

In general, the participants rated their preliminary knowledge low about hepatitis and there was no clear indication that the knowledge would improve.

Participants reported some uncertainties about the aims of the project that they were recruited.

Some participants reported uncertainties about the process of the screening and the way of getting informed about the results.

Some participants rated low the information provision about the possible vaccination against HBV.

Some participants rated low the information provision about the antiviral treatment options.

**CHI-MIG group**

The three Chinese participants in general supported the aims and the process of the project.

They rated the first information session with the child health visitor lower and the information they received about the hepatitis in general.

Two of them expressed that they would expect a bit more on the vaccination and/or treatment options.
### General Aim:
To explore the attitudes and perceptions of migrant women who participated in the implementation of the prenatal screening programme as part of the Hepscreen project and make possible proposals for improving future interventions.

### Specific aims | Questions
---|---
**Specific aim 1:** To explore aspects related to the counselling (visit) of the local and regional child health visitor (CHV)
- How do you feel about the health visitor’s counselling session?
- What motivated you to participate in the study?
- During the CHV’s visit, what was told you about HBV and HCV? Was this info new to you?
- Was it clearly explained to you?
- What about the communication issues? Did you experience language barriers or difficulties? If yes, how were they solved?
- What about the materials that were used (mini-interview, data collection, information leaflet)? Were they adequate?
- What do you think of the CHVs’ work and attitude? Were they helpful, informative, etc.?
- If you had any doubts about the counselling section and/or the study, how was it resolved?

**Specific aim 2:** To explore the perception about accessibility to participate in the different phases of the study
- When you agreed testing, did you know where and how to do it? Was it explained to you by the HCV or by anyone else?
- Did you receive any support from the CHV to get access to testing? If yes, how?
- How long did it take between the counselling section and getting an appointment? If too long, why?
- Was it difficult to get an appointment?
- Did you feel / experience any negative feelings about going to get tested? If yes, what were these (shame, stigma, etc.)?
- Did you share your experience of getting access to testing with your CHV?

**Specific aim 3:** To explore aspects related to the healthcare received (serology sample taking, treatment)
- How did you feel during medical visits and during the serology sample taking? What are your impressions, memories?
- What do you think of the medical staff’s work and attitude when you had your blood sample taken? Were they helpful, informative, etc.?
- Did you have any problems of communication with the medical health staff? How was it resolved?
- Were you clearly explained what happens next after the test? if yes, by who and how?
- How did you find out your results (HCV, HBV)? Did you experience any difficulties? Did you get help?
- How long did it take to get your results? If too long, why?

**Specific aim 4:** To explore the perception on aspects related to the hepatitis (risks, fears, care, etc.)
- Do you think the study was useful in providing information about hepatitis B or C? If yes, how?
- Did you have any negative feelings after hearing about viral hepatitis B/C? Such as fear, shame, stigmatised, confusion etc?
- Did you share these feelings with anyone? With whom and how? Was it helpful?
- Do you have any positive feelings after hearing about viral hepatitis? Such as wanting to be healthy, wanting to have a healthy baby, the need to take care of your health, understanding your own health more, wanting to protect your
family, that fact that it can be cured, empowered, greater awareness about this virus and the risks.
- Is your community at risk?
- Do you think there is a high level of awareness of these viruses/diseases within your social/network community?
- Do you / can you discuss this issue within your community?

<table>
<thead>
<tr>
<th>Specific aim 5: To explore proposals for implementation of screening system for migrant population.</th>
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<tbody>
<tr>
<td>- Would you get tested again in the future?</td>
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<td>- Would you recommend to your friends to get tested?</td>
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<td>- Do you think that people in your community should also get tested? / Would you recommend other mothers to get tested?</td>
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<tr>
<td>- What methods/strategies do you think would be most effective for screening tests in your social network / community? How would you contact them?</td>
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**Appendix II – Attitude statements sheet**

Voting stickers

**Attitude statements sheet**

This sheet is anonymous, please do **NOT** put your name on it!

Your age: ........................................ years  
How long have you been living in Hungary? ........................................ years

Your country of origin: ........................................................................

Please answer the following questions by *rating*.

1 is the minimum – **No, not the least.**  5 is the maximum – **Yes, very much / very good.**

You can also state *I do not know / I do not answer (NA).*

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<th>Counselling meeting with the child health visitor</th>
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<td>1. How would you assess your knowledge about hepatitis C and B before the counselling meeting with the child health visitor?</td>
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<td>2. How would you assess your knowledge about hepatitis C and B after the counselling meeting with the child health visitor?</td>
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<td>3. How would you assess the usefulness of the counselling meeting?</td>
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<td>4. Did the child health visitor inform you about hepatitis infection clearly?</td>
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<td>5. Did the child health visitor ask the proper questions?</td>
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<td>6. How would you assess the counselling meeting overall?</td>
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<th>Results</th>
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<td>7. Did it go well to get informed about the results?</td>
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<td>8. Was the result clearly explained?</td>
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<td>9. Did the child health visitor inform you about hepatitis vaccination options clearly?</td>
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<td>10. Did the child health visitor inform you about hepatitis treatment options clearly?</td>
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<td>11. How would you assess the work / performance of the health visitor through the screening?</td>
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<td>NA</td>
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<td>12. Have you felt any negative attitude during the study from the staff?</td>
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<th>Screening programme / study in general</th>
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<td>13. Did the study take into account your special needs (language, place, culture)?</td>
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<td>14. Was the study explained well enough?</td>
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<td>15.</td>
<td>How important do you find this study personally?</td>
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<td>16.</td>
<td>How relevant is this study for your community?</td>
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<td>17.</td>
<td>How would you assess the whole study / screening progress in general?</td>
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<td>(in terms of contributing to your knowledge and attitude about the hepatitis)</td>
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<tr>
<td>18.</td>
<td>How would you assess the likeliness of your participation in a study like this?</td>
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<td>19.</td>
<td>How would you assess the likeliness of the people from your community to participate in a study like this?</td>
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<td>20.</td>
<td>Would you recommend your friends to participate in a study like this?</td>
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3 Local community engagement in London – focus group report

Prepared by Lorna Sweeney and Jan Kunkel

3.1 Overall aim

The purpose of the focus groups was to engage with people from at-risk communities targeted by the HEPscreen London screening pilot, in order to gather feedback regarding the communication materials used for the pilot study. The focus groups aimed to explore whether the screening invitation letter and information sheet designed for the HEPscreen pilot were useful, relevant and reassuring, and how the content of these communication materials could be made more appropriate or effective to encourage screening uptake.

The focus group discussions also provided an opportunity to gather feedback on the content of information leaflets about hepatitis B and C developed by the Hepatitis C Trust.

3.2 Methods

Two focus groups were held in September and October 2014, with African and Turkish communities, respectively. Focus group participants were recruited from through local community support and advocacy organisations in Hackney, east London; the site of the HEPscreen London screening pilot.

The first focus group was recruited and organised by Rise Community Action. Six women and two men from the African communities in Hackney attended the group discussion, which was held at a meeting room at the headquarters of the Hackney Council for Voluntary Service on a Saturday afternoon, September 13th 2014. LS facilitated the focus group discussion, which was held in English.

The second focus group was recruited and organised by Day-Mer Turkish and Kurdish Community Centre. Five women and three men attended the focus group, which was held at a meeting room within the Centre on a Friday morning, October 3rd 2014. Five of the participants did not speak English, thus the group discussion was co-facilitated by LS and a bilingual community support worker from the Centre, who was briefed in advance regarding the objective of the focus group discussion and the nature of the questions.

Focus group procedures were approved by the National Research Ethics Service, Brent, London, as a minor amendment to the approval for the HEPscreen pilot study. All focus group participants provided written informed consent for audio recording of the discussions and for anonymised data to report the focus group findings. A topic guide was used to pose questions to the group, but the group discussion also provided space for topics raised spontaneously by the participants. LS initiated each group discussion by asking participants about the kind of relationships they felt that people from their communities had with their local general practitioners (GPs) and GP services, as the HEPscreen pilot study focused on providing hepatitis (and for some cases, HIV) testing at local GP surgeries. Copies of the communication materials for the HEPscreen pilot study (screening invitation letter and information sheet) were then passed around to each participant, and were also read verbally to the group, in case of literacy issues. A vignette/ hypothetical character from the
participants’ communities was then introduced (e.g. Ms Amaka, an African lady living in Hackney) and participants were then invited to imagine that the character had received the screening invitation letter and information sheet in the mail and to make suggestions for how she might respond, and why. LS also probed responses to the specific content of the communication materials during the group discussion. The HEPscreen pilot study also measured whether the inclusion of HIV in the screening invitation had an effect on screening uptake; thus, participants were also asked for their opinions and perspectives on this. Finally, participants were provided with copies of the information leaflets developed by the Hepatitis C Trust and asked for comments and feedback on the content of the leaflets.

The focus group discussions were 1.5-2 hours in length and each participant received £30 as reimbursement for the time and travel costs involved in their participation.

3.3 Findings

3.3.1 Findings in relation to the HEPscreen pilot study

Participants in the African focus group largely perceived that people from their communities would be unlikely to act on the screening invitation provided by the HEPscreen study. The reasons for this are outlined below.

In the Turkish focus group, some participants said that they themselves would be willing to take part in the HepFree study and attend for screening, as they felt it was a good opportunity to learn more about the illness and to get treated if they have it. LS encouraged participants to also consider the likely responses of people from the wider Turkish community and participants suggested a number of factors which may affect willingness to act on the screening invitation, as outlined below.

3.3.2 Relationships with GPs

The challenges of interacting with local GP services and developing good patient-doctor relationships differed between groups. In the focus group with African people, many of the participants felt that GPs do not provide their patients with sufficient time and attention, which can discourage people from their communities from attending the GP. Participants referred to occasions when they felt dismissed by their GP, or that the GP was not interested in discussing healthcare options with them. Lack of continuity of care within local GP services also lead some to feel they are not receiving good quality care.

“It depends on the GP. Some of them are really difficult, some are easy. But the main problem is they don’t give you time. You go in with a problem and they give you a prescription before you even sit down. So that puts off people. They only go there when they are really, really desperate.”

[Participant 6, Male, African group]

“The GPs, they don’t have time for you as an individual. Sometimes you want to just express yourself and it’s like you should just be dealt with and go...I feel quite intimidated or reluctant, honestly, to willingly go to my GP surgery.”

[Participant 7, Female, African group]
In the group discussion with Turkish people, participants focused on the language barrier that prevents them from communicating with their GPs. One participant stressed that the lack of interpreters at GP services impacts on the health of the community, as people experience greater delays in treating or resolving health issues. The language barrier at the GP surgery was also expected to discourage some people from acting on the HEPscreen invitation letter.

“She said that she’s got a good relationship, but obviously the language barrier is one of the problems for her. For example, sometimes she can’t explain properly and they don’t provide interpreters.”

“He says the language is the biggest problem. That’s the most common problem. He says, ‘We can’t explain our problems without interpreter’.

[Participant responses translated by co-facilitator]

In both groups, long wait times at GP surgeries were also suggested to put people off attending for optional hepatitis screening, if they feel they do not have the time to participate.

3.3.3 Attitudes towards research studies

Participants in the African focus group said that negative views about research studies and/or researchers are held within their communities, due to the belief that people do not typically receive any benefit from taking part in research and often do not even receive any feedback on research studies in which they have participated. Therefore, participants believed that many people within their communities would be discouraged from acting on the invitation to test for hepatitis at their GP surgery if the communication about the testing comes from a research group, as it does for the HEPscreen study. Some participants also indicated that people are accustomed to being reimbursed for participation in research projects and therefore may not see any benefit in participating in the HEPscreen study, as no reimbursement is offered.

“And this particular letter would put me off. Testing for hepatitis will benefit me, but the word research would put me off. Because then the ownership of my benefit now gets away from the whole thing and goes to the researcher...I feel like I’m a guinea-pig being used to get you what you want. So that would be a put off. I would just say I might aswell go to a clinic and get the test, why do I have to go through them? (the researchers)”

[Participant 1, Female, African group]

Participants in the African focus group also suggested that people from their communities may be suspicious about how their information will be used if they participate in the research study. In particular, there may be fears that their immigration status may be under
investigation. Participants also thought that some people may mistrust the authenticity of letters that claim to have come through their GP service, due to previous scams through Hackney GP mailing systems that were well-known within the community. For this reason, participants suggested that the HEPscreen study should work with community organisations in order to recruit people for screening, because of the trust that people have in these organisations.

“These words ‘researchers’, ‘professors’, to the normal people it means something different. If you’re a researcher are you going to research on my immigration status aswell? Are you going to research on my family affairs? They don’t know how far does the research go?”

[Participant 5, Male, African group]

In contrast, participants in the Turkish group discussion did not indicate any problems with the involvement of a research group in hepatitis screening at GP surgeries. Participants saw it as informative that the researchers would find out how many people have hepatitis B and C within their community. Participants also did not indicate that people from their community would have any concerns or suspicions that their health information from the research study would be shared with immigration authorities. One participant even questioned why the information sheet stated that the patient’s information would not be passed to third parties, as she felt that people are accustomed to routine blood tests, where such information is not shared.

While the participants in the Turkish group did not believe the communication from a research group would be off-putting to their community, one participant pointed out that people may be more inclined to actually act on the invitation letter if it was also signed by their GP, or if the GP’s name was contained within it.

“I think having your own GP’s logo, or some sort of name. If I see my own doctor’s name there aswell I think that would make me more attached to the research and I would feel like, ‘Yes, my GP is doing it. I should do it.”

[Participant 1, Female, Turkish group]

3.3.4 Low levels of awareness and knowledge of hepatitis B and C

In both focus group discussions, participants stressed that there was very little awareness and knowledge about hepatitis B and C within their communities. The majority of focus group participants themselves said that their understanding of hepatitis B and C was extremely limited (apart from one participant in the Turkish group who had previously been diagnosed with hepatitis B). Participants suggested that lack of awareness of these illnesses would be a key reason for non-response to a screening invitation, as they felt that hepatitis B and C would be unlikely to mean anything to many people within their communities and that they would be unlikely to be viewed as serious, relevant illnesses. Participants believed that people within their communities were unlikely to perceive themselves to be at risk or in
need of screening, unless they have previously come across hepatitis B and C in their families or networks.

“There is so little information about this. It’s like it doesn’t affect us really. ‘B and C, what is it? Oh well, if I haven’t heard about it then it’s not an issue for us’. So I think there is a need to raise awareness of hep B and C. That it is actually a health issue amongst African communities...So for me to be honest there is a grave lack of information in the African communities, and if anyone sees this, or if I saw this I would say, ‘Oh, it’s not something that affects us’.

[Participant 7, Female, African group]

“The letter assumes that she knows about hepatitis B and C...In most cases she doesn’t know about it. And she won’t be interested to reply about something that she doesn’t know about”... “I’ve never seen anybody with these conditions.”

[Participant 6, Male, African group]

“I think they’d ignore it, that would be one of the things aswell. They’d just like, ‘Ugh, really? I can’t be bothered. I’m sure I don’t have it because I’ve never heard of anyone in the family that had it. So I don’t think I have it. I’ve never had an operation, I’ve never had a problem when they were taking my blood. I don’t remember any connection between my blood, something going wrong.

[Participant 1, Female, Turkish group]

Turkish participants also pointed out that hepatitis B is typically referred to as ‘jaundice’ within Turkey and within the Turkish community. Everyone in the group indicated that they thought of hepatitis B in this way. Participants suggested that the severity of hepatitis B is therefore likely to be underestimated within the Turkish community.

“I thought that jaundice and hepatitis B were the same”.

[Participant 1, Female, Turkish group]

3.3.5 Sensitivity around community being targeted for health screening

Most participants in the African communities group were uncomfortable with the second line of the invitation letter that states “We know that people who were born outside the UK and probably their children are more often infected with hepatitis B and C”. These participants were unhappy with the perceived implication that people are bringing diseases to the UK, as they felt that these illnesses could also potentially affect people from the UK. Participants suggested that the tone of the sentence should be softened by instead stating, ‘some people who were born outside the UK’. In contrast, one of the participants within the group thought that it was OK for the HEPscreen study to target immigrant communities in this way, because statistically the risk is higher for those outside the UK.
“It sounds like that— you are born outside England, you are bound to have disease. Maybe it should say some people who are born outside the UK may have hepatitis.”

[Participant 6, Male, African group]

“But statistically those born outside UK, it is higher. So that’s why the message is being put in this way.”

[Participant 5, Male, African group]

In the Turkish group discussion, participants held mixed opinions on whether people from the Turkish community would be offended that their community was targeted for hepatitis screening. While one participant thought that people would understand that the country is at higher risk, another participant felt that there may be offense within the wider community.

“He said, ‘No, I might just think that Turkey as a geographic location might be the high risk group’”.

[Participant responses translated by co-facilitator]

“I think looking at, not this group, but our general community in London, I think there might be a large number of people that might be offended.”

[Participant 2, Female, Turkish group]

3.3.6 Fear
Some participants in both groups suggested that the recipient of the screening invitation letter may think that their GP service has identified something wrong with their health, which could cause anxiety. Fear of being diagnosed with an illness, or fear of social exclusion if people within the community are aware of their illness, were suggested as potential reasons for non-response to the invitation.

“When people read this letters they sometimes fear that they’re spotted as having that and it creates an anxiety”

[Participant 5, Male, African group]

3.3.7 Tone and content of the invitation letter and information sheet
Participants in the African focus group perceived that the letter and particularly the information sheet were too long and would be off-putting for people in their communities. While the information sheet might be informative, participants expected that people from their communities would not have the time to read through the amount of information it contained. It was suggested to send a shortened version of the letter and information sheet, with the key messages, and then when the patient came in for screening the more detailed aspects of the study could be explained.
“I think for us, for most African communities, we don’t really like reading. I think this is too much literature. I don’t think I’d have time to read all of this”…“It’s just too much literature, they should have simplified it and made it a bit more friendly to read.”

[Participant 1, Female, African group]

“If you design a leaflet just to tell someone to come in for the research and then when they come in that’s when you explain to them what are the dangers, what are the risks, what are the terms. I feel this is a lot more, for the initial…Just invite them to come in and then when they come in you can explain this and this and this”.

[Participant 6, Male, African group]

Participants also felt that the tone of the letter and information sheet was off-putting and that it needed to be “more friendly”. The words used were seen as “heavy”, “confusing”, and “academic and theoretical”, particularly for people who were born outside of the UK and who may not speak English proficiently.

Participants in the African focus group were also uncomfortable with the sentence of the screening invitation letter that stated that the recipient will be contacted a second time if they did not respond. This was perceived as intimidating and the bold print and underline used in the sentence was seen to lend a threatening tone.

“It sounds like they’re bailiffs!...It sounds like ‘We will come after you’”

[Participant 6, Male, African group]

Conversely, participants in the Turkish group believed that the inclusion of this sentence was a good idea, as it was more likely to encourage people to get in contact. Participants viewed multiple letters on the same issue from the GP surgery or the NHS to be common procedure.

Participants in both focus groups were uncomfortable and confused by the section in the information sheet entitled ‘What happens if something goes wrong?’, as the information within this section did not state what kind of problems could arise, and whether these were in relation to the screening or the treatment process. The references to potential harm or problems, and potential payment for legal action, were thought to discourage people from getting involved with the study. Furthermore, there was perceived to be an insinuation that the research team would not have to accept any responsibility if problems arose. One participant in the African group also queried whether this section referred to the testing of hepatitis drugs on those who participate in the study.
“...the last bit goes wrong when it talks about that one may pay for it (legal action). It can be quite a deterrent to be quite honest, because some people are suffering to have a plate for their daily living, so if you know that legal action might be taken. Whoever is doing this research is actually benefitting from you. So it’s like, ‘Well they are benefitting and I might end up being in court or being asked to pay for this, that and the other’.”

[Participant 7, Female, African group]

“He said, ‘It says that if something goes wrong you might have to go and pay your own fees and that might just put people off as well.’”

[Participant response translated by co-facilitator]

“And even the fact that there’s a possibility of something going wrong is a bit scary.”

[Participant 1, Female, Turkish group]

In both focus groups, one aspect of the letter and information sheet that was perceived to encourage attendance was the information that people who have hepatitis B/ C are often unaware that they are infected. Participants in the African group also suggested that the key messages to encourage people to attend screening that ought to be included on a shortened version of the letter/information sheet included the information about hepatitis B and C, the treatments available, and the information about confidentiality. Participants in this group also suggested that the screening letter/information sheet ought to more adequately communicate what is actually under study in the HEPscreen research.

Participants in the Turkish group were pleased that the invitation letter and information sheet were provided in the Turkish language and they felt that this would increase people’s willingness to respond.

“She said, ‘Because it’s in Turkish I would be happy to receive that information’.”

[Participant response translated by co-facilitator]

“People would actually feel, ‘Oh, they’re caring about people that can’t speak English and they’re doing something positive for us’.”

[Participant 2, Female, Turkish group]

Participants in the Turkish group also suggested that future versions of the information sheet ought to contain more specific examples about how one may have contracted hepatitis B or C in their home country.
3.3.8  **Inclusion of HIV screening expected to reduce uptake**

In both focus groups, participants believed that responses to the HEPscreen invitation letter would be lower if HIV testing was offered alongside hepatitis testing. This was attributed to the stigma of HIV within participants’ communities. It was suggested that HIV screening should be separated from the screening of hepatitis, in order to prevent the same stigma being applied to hepatitis. The Turkish participants said that HIV was perceived within the community as a common illness for African countries, and not an illness for Turkish people.

“I think you should separate HIV from the whole issue, because though it has been here for many years there is still a lot of stigma attached to it. So I can be free to say, ‘They’ve checked me for hep B and hep C’, but I can’t be free to say I’ve been checked about HIV. So I think you should separate it...Because the way you were explaining before about hepatitis B and C and using unsterilised needles, but when you include HIV then people will relate it to sleeping around, so you will lose the meaning.”

[Participant 2, Female, African group]

“B and C, it’s kind of OK. If you have HIV there they would never go.”

[Participant response translated by co-facilitator, Turkish group]

3.4  **Findings in relation to the Hepatitis C Trust information leaflets**

Participants in both focus groups generally responded very positively to the information leaflets developed by the Hepatitis C Trust. Participants in the African focus group consistently emphasised that the explanations about hepatitis B and C were better and clearer in the leaflet than in the information sheet that had been provided for the HEPscreen pilot. In both focus groups, it was suggested that the information leaflet should be included with the screening invitation letter when it was sent out to patients. Participants in both groups agreed that the leaflet was something that they would feel comfortable sharing with friends, or giving to someone who they thought might be at risk for hepatitis B or C, and they believed that the leaflet would encourage someone to go for hepatitis screening.

However, participants in the African group did not like the use of two languages in the same leaflet; particularly that French was on the left side of each page, as this was then read first automatically which they found confusing. Participants in this group also felt the use of two languages caused the font size to be too small and gave the impression of too much information in the leaflet.

“Because to be honest one feels quite bombarded with this information, the font becomes very small, because they are trying to fit in so much. So if it’s English, if it’s one language then the font would be quite user-friendly than what it is now.”

[Participant 8, Female, African group]
The co-facilitator of the Turkish group also pointed out that the Turkish translation of the information leaflet was not as good as the translation of the HEPscreen communication materials. She felt that the leaflet may have been translated by someone who spoke Cypriot Turkish and who is not fully accustomed with mainland Turkish.

The groups discussed the specific content and wording of each section of the leaflet in turn, as outlined below.

**LEAFLET COVER**

Participants in both groups liked the cover, which was thought to be “nice and simple” and “prepared well”. Participants in the African focus group liked that the cover stated that hepatitis B and C were found in many countries, which was viewed as non-discriminatory.

“It says that it is found in many countries which is good, it doesn’t pick up on one country, which is good”.

[Participant 7, Female, African group]

**INFORMATION SECTION**

**Section 1: What is hepatitis?**

- In both focus groups, participants thought the content of this paragraph was well explained and was informative.
- Participants in the African focus group thought it was beneficial that the leaflet highlighted that most people do not know whether they are infected with hepatitis B or C.
- One participant in the Turkish group pointed out that the use of the word “cancer” was helpful in this paragraph, as while many people may not be aware of hepatitis, everyone is aware of cancer. This was felt to highlight the importance and the seriousness of hepatitis B and C to the reader.

Another participants, who himself had been diagnosed with hepatitis B pointed out that hepatitis does not always lead to cancer (referring to his mother, who was a carrier at 73 years of age). He therefore felt that the language used was quite frightening, but others in the group disagreed and felt that it conveyed that hepatitis B/ C should be taken seriously.

**Section 2: Why get tested?**

- Participants in the African focus group were mostly satisfied with the explanations provided in this section. One participant thought that the sentence ‘Treatment for hepatitis B can stop you getting very sick’ was unclear, as the term ‘very sick’ was believed to be too vague. Another participant was uncomfortable with the statement ‘your family can be vaccinated’ as she felt it may be very difficult for the patient to get their family to go for vaccination.
“How would you get your family to go get vaccinated? Even if it’s TB you find that it is hard to get, I know this disease is not very highly stigmatised, but getting your family to get vaccinated”… “How would you tell your husband, your family…I thought that was a bit uncomfortable”.

[Participant 1, Female, African group]

- Participants in the Turkish focus group thought this section of text was confusing, as the information about hepatitis B and hepatitis C kept interchanging throughout the paragraph.

“...All the B’s and the C’s ...And the sentences are not...how can I put it? The way that the wording is done is quite confusing for people, it could be a bit simpler... ... I would need to read it again”. [Co-facilitator]

In general, participants in the Turkish group perceived that the section was contained too much information for people, particularly as the information would be explained by the doctor anyway when the person attends for screening. In particular, it was felt the information on ‘If you do not have hepatitis B/C...’ could be removed. Participants pointed out that first-generation Turkish immigrants living in London frequently have low levels of education and are uncomfortable with reading, thus the amount of information in this section would be difficult for many people to comprehend.

“Just to add to what she said, we talked about the level of education within the community, it would be very difficult for them to gather all that information.”

[Participant 2, Female, Turkish group]

Section 3: Will you have legal problems if you test positive?

- The two focus groups held very different perspectives on this section of text. In the African focus group, participants felt this was a very important issue to be clarified for the reader and they pointed out that such a statement had been missing from the HEPscreen invitation letter and information sheet.

“I think this is very good, because I’ve heard of people who wouldn’t take HIV tests because of the implications of HIV and legal. So it’s good for people to know that this will not have anything to do with their legal status”.

[Participant 1, Female, African group]

- Conversely, some participants in the Turkish group thought this section was confusing, as they felt that it did not clarify what was meant by ‘legal problems’.
“What do you mean by legal problems? It’s not clear... Legal problems could be anything. Your rights with the NHS, your treatments, so it does cover a lot of things”.

[Participant response translated by co-facilitator, Turkish group]

LS explained that the reasoning behind this section was that some people who move to the UK might fear that if they get a diagnosis of an illness such as hepatitis they might be sent back to their home country. LS asked how participants how the section could be rephrased in a better way. It was suggested to state clearly that if you have moved to the UK from abroad and you are found to have hepatitis B or C, your legal status in the UK will not be affected. It was suggested that the section should also state that the information between you and your GP will be confidential.

Section 4: How could you have caught hepatitis B or C?

- Participants in both focus groups were happy with the content of this section and thought the information on how hepatitis B and C are acquired was explained very well.

Participants in the African group were pleased that this section emphasised the mother-to-child route transmission for hepatitis B, which was believed to reduce potential stigma.

“This is very good, because putting ‘your mother’ there and not putting sexually transmitted makes it cleaner... Even HIV you can get from your mother, but they highlight sexual intercourse”.

- Participants in the African focus group also liked that this section listed regions in the world that are affected by hepatitis, rather than stating that “people born outside the UK” are at risk (as was stated in the HEPscreen letter).

“We have gone through a lot as African people, so they are saying ‘outside’, but really they are after... But if it’s like this, such as Asia, Africa, Latin America, yeah I would be more comfortable. That’s very important.”

[Participant 1, Female, African group]

- In the Turkish focus group, participants liked that the section provided examples of how hepatitis C can be acquired through toothbrushes [I think it refers to dental equipment in the text] and shaving equipment, as this was useful information for families.

BACK PAGE

- Participants in the African group thought that the colours used in the world map images ought to be brighter, or contrast with one another more strongly, in order to more easily identify the prevalence rates by country.

“I think the colouring is not very different, between West Africa and the other parts of Africa. It’s not very distinct.”

[Participant 5, Male, African group]
In relation to the map key, participants in the African group were confused by the “the question mark over the whole of Africa for hepatitis C”. LS explained that this was in relation to unknown data on rates of hepatitis C in Africa, but participants felt that further explanation was required on the leaflet, rather than just a question mark.

“I thought maybe it was because we are free from it!”

“Oh too much of it!”

[Male participants, African group]

Participants in the Turkish group found the map key to be very confusing, because there are 10 different boxes of colours. LS pointed out that there were two boxes for each colour because of the two different languages in the leaflet, but participants suggested that there should instead be only 5 colour boxes and each box should just contain the two versions of the word beside it, e.g. “Yuksek/High”.

Participants also pointed out that incorrect Turkish words were used in the map key. ‘Orta’ means intermediate, and was used for the ‘High intermediate’ box, but then a different word ‘dusuk’ was used for intermediate in the ‘low intermediate’ box. Participants indicated that the word ‘dusuk’ was not commonly used in their community. The word ‘pes’ which was used for ‘low’ was also felt to be incorrect.

In relation to the contact details and helpline listed for the Hepatitis C Trust, participants in the African focus group felt that many people would not want to call these numbers because 0845 numbers are typically very expensive. Participants suggested that if the contact number is a free phone number, this should be clearly stated on the leaflet.

Participants in the African group felt that the information about testing at the Hepatitis C Trust would be appealing, in comparison to organising screening at the GP practice, because the Hepatitis C Trust was expected to have greater support structures in place.

It was not possible to discuss the Hepatitis C Trust contact information section in the Turkish group because the entire section was written in English.

The ‘Additional Information’ section is written in two different, non-relevant languages, thus it was not possible to discuss this section in either of the focus groups.
4 Local community engagement in Barcelona – focus group report

Prepared by Constanza Jacques Aviñó and Manuel Fernández Quevedo

4.1 Project Summary
Within the framework of the Barcelona pilot, which forms part of the HEPscreen project, three focus groups and two individual interviews were held involving 27 people from Latin America and Central and Eastern Europe, who were contacted using an active strategy. Through these focus groups, participants indicated that they were satisfied with having participated in the screening programme, and appreciated the free use of the health service in Spain and the incentive awarded. The people who participated in all stages of the study represent a specific profile that tends to be motivated to know and care more about their health status. There was a greater perception of risk and stigmatisation about hepatitis among individuals from Central and Eastern Europe. For future screening projects, it is important to consider immigrants’ perception of the disease in question, and their experiences with the health care systems in their home countries.

4.2 Introduction
Within the framework of the HEPscreen project, the Barcelona pilot project consisted of three focus groups and two brief interviews conducted between April and July, 2014. A total of 27 people from Latin America (LA) and Central and Eastern Europe (CEE) were contacted. The sample was recruited using an active strategy and all individuals were involved in all phases of hepatitis screening, i.e. were present at the educational sessions conducted by community health workers, had a visit with the doctor (after which they were given a transportation card as an incentive for their participation), and had visits to give a blood sample and to collect the results.

The aim of this study was to gauge, using a qualitative methodology, the subjects’ perception of their participation in this project, and proposals for screening in the immigrant population. At the end of each session a dynamic score was created using ‘sticker voting’, which allowed us to evaluate participants’ perceptions of the study more anonymously, and to summarise these for the entire group.

We initially intended to conduct two focus groups within each population group in our pilot study. However, we had considerable difficulty in recruiting participants, especially those from Romania, who represent a significant proportion of Eastern European immigrants. Thus, we were able to perform the following actions:

- a focus group with the Latin American population, including 8 participants;
- a focus group with people from Russian-speaking countries, including 8 participants;
- two brief interviews with Romanian people;
- a focus group with the Latin American population, including 9 participants.
This document describes the aims of the focus groups, the methodology used, and the results of each session, as well as final conclusions and recommendations. The annex contains copies of the various documents used to collect data in this project.

4.3 Aims

4.3.1 General Aim
Gauge perception of the implementation of the active strategy among participants who completed all phases of the hepatitis screening program within the Barcelona Pilot study, and to gather their proposals for improving future interventions.

4.3.2 Specifics aims
- To evaluate aspects of the Educational Sessions (ES) carried out by Community Health Workers (CHW)
- To gauge perception of accessibility to participate in the different phases of the study
- To evaluate aspects of the visits and the health care received (counselling, understanding the study, diseases, etc.)
- To gauge perception of aspects of hepatitis (risks, fears, care, etc.)
- To gather proposals for implementing a screening system among immigrant groups

4.4 Methodology
Participant recruitment was carried out two weeks before the date scheduled for the Focus Group (FG). Participants were contacted by phone and two possible dates were proposed from which to choose. Finally, the date and time that best suited most of them was proposed. All individuals who participated in the focus groups were required to sign two documents, the first giving permission to use their image, and the second confirming that they had received the incentive offered, both translated into the participants’ own language (Annexes 8.1, 8.2, 8.3).

The discussion was guided by a moderator who acting as a catalyst, and a second moderator who acted as an observer. Sessions among CEE participants were grouped by language. A supplemental cultural mediator for participants from former USSR countries and for Romania was provided to ensure correct understanding and interpretation of the participants' questions and answers.

The sessions were held at a convenient location for participants.

Group size, recruitment and set-up
- Inclusion criteria: participants in the active strategy who underwent the entire study process (from educational session to laboratory result).
- Recruitment: via telephone call
- Group Size: 6 to 10 persons
- Meeting timeframe: approximately 60-90 minutes, with coffee break at the end of the session
- Incentive: 30 euro gift voucher for El Corte Ingles Department Store (note that this is distinct from the incentive of a transportation card offered for participating up to the stage of the medical visit, which was evaluated in these focus groups).

Content of FG
- The FG began with a presentation of the meeting’s aims, and introduction of each participant. Participants were asked their names, country of birth, and about any activity that they liked to do, which served as an icebreaker exercise
- First part: comment on and discuss various issues related to the specific aims
- Second part: Perform “sticker voting”. The moderator asked a question and participants answered by placing a sticker next to various statements (related to the specifics aims) that correspond to the 5 response variables. The question were written on cards and pasted on the walls of the meeting room. Stickers were given to each participant in order to make their evaluation (Annex 8.4).
- Example Cardboard:

<table>
<thead>
<tr>
<th></th>
<th>Very bad</th>
<th>Bad</th>
<th>Regular</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you assess the educational session in general? (Includes location, timing, language, CHW attitude ...)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What do you think of a metro card as an incentive to participate in the study?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What do you think of the possibility of hepatitis testing in people from your country?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Question and answer session about viral hepatitis
- Feedback and closing

Records
- Demographic data (age, sex, ethnicity, place of birth, legal status, etc.) were provided in writing anonymously
- Audio visual media recording of the session, for which all participants were required to give consent.
### Data collection

All individuals who formed part of the team involved in carrying out the focus group (moderator, camera operator, observer, cultural mediator) met one or two days after the session to:

- view the video together
- make a transcript of the session together
- comment on the notes made by the observer
- comment on their perceptions regarding the attitudes and dynamics of the participants
- re-read the results of what was written and discussed

Then the moderator gather all information and compiled it in a report.

### Script of questions

We first identified the specific objectives, then indicators, and finally questions that would serve as a guide during the FG. Two main questions were chosen by targets, and the others were used only where necessary to motivate participants and/or to gather detailed information about the topics in question.

<table>
<thead>
<tr>
<th>Specific aims</th>
<th>Indicators</th>
<th>Questions</th>
</tr>
</thead>
</table>
| **Specific Aim 1:** To evaluate aspects of the Educational Sessions (ES) carried out by Community Health Workers (CHW) | - Motivation for going to ES  
- Contact strategy (direct, telephone call, through third-party, etc.)  
- Location (conditions of physical space)  
- Timetable and duration  
- Day  
- Accessibility  
- Media and materials used  
- Language used and ease of understanding | - How did you find out about this ES?  
- What motivated you to participate in the study?  
- Was it easy or difficult to access? (place, time, etc)  
- What did you think of this session?  
- Was the study clearly explained to you?  
- What did you think of the location? Was it comfortable?  
- Were the materials used adequate?  
- What do you remember?  
- Do you know anything about hepatitis?  
- What language was used during the session?  
- Was it easy/difficult to understand issues related to hepatitis?  
- What did you think of the CHW’s attitude?  
- Were doubts about hepatitis and the study resolved satisfactorily? |
| **Specific Aim 2:** To gauge perception of accessibility to | - Time elapsed between ES, physician appointment and blood sampling  
- Adaptation to the dates and times proposed according to availability  
- Access to the healthcare facility (distance, ease of access...) | - Did you have to wait a long time between the SE and the call for a doctor’s appointment?  
- Was your availability for the appointment taken into consideration?  
- Did you get a reminder about the doctor |
<table>
<thead>
<tr>
<th>Specific Aim 3:</th>
<th>Specific Aim 4:</th>
<th>Specific Aim 5:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participate in the different phases of the study</td>
<td>To evaluate aspects of the visits and the health care received (counselling, understanding the study, diseases, etc.)</td>
<td>To gather proposals for gathering proposals for awareness of the need for hepatitis screening in your community</td>
</tr>
<tr>
<td>- Appointment reminder</td>
<td>- Associations made with hepatitis</td>
<td>- Awareness of the need for hepatitis screening in your community</td>
</tr>
<tr>
<td>- Staff Attitude</td>
<td>- Perception of individual and community risk</td>
<td>- Perception of health problems and the need to screening for other diseases in the community</td>
</tr>
<tr>
<td>- Opinions on the incentive</td>
<td>- Perception of harm</td>
<td>- awareness of the need for hepatitis screening in your community</td>
</tr>
<tr>
<td></td>
<td>- Emotional response to hepatitis</td>
<td>- Perception of health problems and the need to screening for other diseases in the community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Of all diseases in your community, how</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
implementing a screening system among immigrant groups

- Proposals for contacting members of the immigrant population, of both the same and other origins
- Options for future incentives

important do you think hepatitis is?

- What strategies do you think would be most effective for screening in your community?
- How would you contact with them?
- What type of incentives would be effective?

4.5 Results

While the initial protocol aimed to carry out four focus groups, two among Latin Americans and two among Eastern Europeans, it was not possible to carry out the session for people from Romania. Given that it was attended by only two people, and with a half hour difference between their times of arrival at the session, we considered it convenient to take advantage of their attendance to ask them some questions based on the information collected in the focus groups.

Thus, we present the following results below:
- a focus group with the Latin American population, including 8 participants;
- a focus group with people from Russian-speaking countries, including 8 participants;
- two brief interviews with Romanian people;
- a focus group with the Latin American population, including 9 participants;

4.5.1 Focus group with the Latin America

Date: 16th April 2014

Location: The session took place in a Reception House for people from Eastern Europe, in a space commonly used as a chapel.

Duration: 60 minutes, plus 20 minute for refreshments

Moderator: Constanza Jacques
Observer: Jesús Edison Ospina
Camera Operator: Manuel Fernández

Participants:

<table>
<thead>
<tr>
<th>Nº</th>
<th>Place of birth</th>
<th>Year of arrival</th>
<th>Sex</th>
<th>Age</th>
<th>Health Card</th>
<th>Residence Permit</th>
<th>Educational level</th>
</tr>
</thead>
<tbody>
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<td>Bolivia</td>
<td>2006</td>
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<td>38</td>
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<td>No</td>
<td>Higher studies</td>
</tr>
<tr>
<td>3</td>
<td>Ecuador</td>
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<td>38</td>
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<td>Secondary</td>
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<tr>
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<td>Ecuador</td>
<td>2003</td>
<td>M</td>
<td>38</td>
<td>Yes</td>
<td>Yes</td>
<td>Primary</td>
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<tr>
<td>5</td>
<td>El Salvador</td>
<td>2010</td>
<td>F</td>
<td>35</td>
<td>Yes</td>
<td>No</td>
<td>Higher studies</td>
</tr>
</tbody>
</table>
The main responses regarding the aims were as follows:

**Aim 1**  
*[To evaluate aspects of the Educational Sessions (ES) carried out by Community Health Workers (CHW)]*

- Participants had a good appreciation of the educational sessions, in terms of both the place and the content
- A couple of Colombians said that thanks to the project they got a health insurance card
- One of the reasons for participating in the study was health, and the possibility of having access to a free health care system
- The majority of participants said that they did not know what hepatitis was before participating in the project.
- The limited information available about hepatitis was related to child vaccination

**Aim 2**  
*[To gauge perception of accessibility to participate in the different phases of the study]*

- The participants had a good perception of the time elapsed between the educational session and the medical visit, which took no more than 8-9 days
- There was easy access to the health care system
- There was a good appreciation of the incentive (transportation card). One person said that they would also have participated without incentive.
- The conversation took a turn toward the health card, and there began to emerge a series of questions about how it is processed, how is renewed, etc.
- In general, participants mentioned that they don’t usually go to their GP to be tested regularly, but rather when there is a health problem. A Colombian couple mentioned that one of the reasons for not having access to the health care system is the lack of a health card.

**Aim 3:**  
*[To evaluate aspects of the visits and the health care received (counselling, understanding the study, diseases, etc.)*]

- There was a good perception of the GP’s attitude
- Participants mentioned that the GP’s did not explain the HEPscreen project or hepatitis issues, but they perceived that this was not necessary because they understood this from the ES
- There were various questions on hepatitis A and participants started to do some questions about it.
Aim 4:
[To gauge perception of aspects of hepatitis (risks, fears, care, etc.)]
- Participants mentioned that their involvement in the project allowed them to adopt preventive measures, for example, some mentioned that had been vaccinated against hepatitis
- Although they found it difficult to establish a mental image of hepatitis, some participants said that they imagined it as a rotten apple, or an insect that they could not see, but that does them harm
- A participant from Colombia said that he had liver problems, and asked a series of questions about this. The conversation focused on answering his questions, until it was decided to stop, and it was recommended that he discuss this at the end of the session, in order to be able to continue with the objectives of the FG.
- Some participants mentioned that they had recommended participation in the project to others due to the incentive.

Aim 5:
[To gather proposals for implementing a screening system among immigrant groups]
- In general, there was no perception of hepatitis risk in their communities.
- When asked what health problems affected their community, they cited HIV/AIDS, syphilis, Chagas Disease, and sexually transmitted diseases.
- In the discussion, some men said that not everyone was interested going to the doctor and being healthy, which was generally in disagreement with the opinion of the women, who thought that people wanted to be healthy
- Some participants suggested that we could contact people from their countries of origin at cultural events; for example, a Bolivian man suggested “fraternity parties”.

Results of "sticker voting"

<table>
<thead>
<tr>
<th>Statements</th>
<th>Very bad</th>
<th>Bad</th>
<th>Regular</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.- How would you assess the educational session in general? (Includes location, timing, language, CHW attitude ...)</td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>2.-How would you assess what you learned about hepatitis during the educational session?</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>3.- What did you think of the access to the different medical visits?</td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>4.- What do you think of a metro card as an incentive to participate in the study?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>5.- What did you think of the attitude of the health staff during the various appointments?</td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>6.- What did you think about how they explained the different issues related to the study during the various appointments? (including topics related to hepatitis, tests, vaccines, etc.)</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>
Observations:

- In general, the group was participatory, although the discussion was less dynamic at the beginning, with some differences in participation depending on the topic.
- Responses and comments were heterogeneous, probably due to the participant’s different educational levels, by differences in their motivation.
- One of the participants attended with her small daughter, which likely influenced her level of concentration and response.
- While women were in the minority, 2 participated very actively during the session.
- The duration of the session was appropriate, and most of the participants focused on the questions while the moderator gave pertinent feedback when necessary.
- Sometimes condescending responses were observed.
- In general, participants were grateful of the opportunity to participate in the study.
- The snack at the end of the session served to relax the atmosphere and share stories in a more informal setting.

4.5.2 Focus group with Central and Eastern Europe (CEE)

Date: 12th June 2014
Location: The session took place in a meeting room at Barcelona Public Health Agency
Duration: 80 minutes, plus 15-minute for refreshments
Moderator: Constanza Jacques
Observer: Sandra Manzanares
Camera Operator: Manuel Fernández
Cultural mediator: Pau Freixas

Participants:

<table>
<thead>
<tr>
<th>Nº</th>
<th>Sex</th>
<th>Place of birth</th>
<th>Year of arrival</th>
<th>Age</th>
<th>Health Card</th>
<th>Residence Permit</th>
<th>Educational level</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Ukraine</td>
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<td>54</td>
<td>Yes</td>
<td>No</td>
<td>Secondary</td>
</tr>
<tr>
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<td>M</td>
<td>Georgia</td>
<td>2010</td>
<td>62</td>
<td>Yes</td>
<td>No</td>
<td>Higher studies</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>Russian Federation</td>
<td>2000</td>
<td>38</td>
<td>Yes</td>
<td>Yes</td>
<td>Higher studies</td>
</tr>
</tbody>
</table>
The main responses regarding the aims were as follows:

**Aim 1**

*To evaluate aspects of the Educational Sessions (ES) carried out by Community Health Workers (CHW)*

- Participants said that they went to the ES because it was free and that they understood the contents of the ES.
- Participants felt that the project was a favour to them that should be taken advantage of because we are all at risk of getting sick.
- Participants said that hepatitis is taboo in their country.
- Participants said that they only go to the Doctor for emergencies, but not for regular check-ups, and that they participated in this project so as to have a medical check-up.
- One participant said "I don't know much, but I know that we must take care of ourselves", while others said that hepatitis is not curable, it is dangerous.
- One participant said that "there are more risks in those countries than here, and I have advised my husband".
- Two women said that they have no health insurance card, and that they participated because they would have the possibility of undergoing more tests.

**Aim 2**

*To gauge perception of accessibility to participate in the different phases of the study*

- Some participants confirmed that enough time had passed between the ES and the visit with the doctor, about 2 months, approximately.
- A participant said "that with our group it is very difficult because they change jobs"; one of the cultural mediators said that he was trying to call people to remind them about the visits.
- It was mentioned that in some cases there are access problems for those who do not have money for transportation.
- In general, there was a perception that the process, including the different stages, was long, although one woman says that the entire process was very fast, and that she was invited to participate in the study via a hepatitis contact study.
- In general, the participants did not know much about hepatitis before the study.
- Some participants said that people have access problems depending on their type of job; one woman explained that she cares for her children, and that it was very difficult to organize herself to go.
- In general, there was no perception of difficulty in accessing the health centre that carried out the screening.
- One participant said that there were problems with the transportation card, in that it had expired because it coincided with the change of calendar year.
- A participant said that if there had been no incentive of the transport card, not all would have participated - "if people don't have enough to eat, they will not attend"

**Aim 3**

[To evaluate aspects of the visits and the health care received (counselling, understanding the study, diseases, etc.)]

- In general, there was a good perception of the health care system in Barcelona.
- It was mentioned that the doctors explained what types of analysis would be done, although there was criticism that sometimes the doctors looked more at the computer than at the patient.
- Most participants said that they had the perception of having learned more in the ES than in the visit to the doctor; however, they also said that they did not feel it was necessary to receive information from the doctor.
- There was a good perception of the questions in the survey.
- Cultural mediators were not always available for patients who attended the health centre; in some cases when there were communication problems between the patient and the physician, a family member or other person had to intervene.
- One of the female participants had regularly served as mediator, and accompanied others during their visit with doctors.
- In one case, a mother entered with her son and did not want to leave although the son did not want to respond to the questions.
- One person said that they never gave answers to the survey questions.

**Aim 4**

[To gauge perception of aspects of hepatitis (risks, fears, care, etc.)]

- The cultural mediator asked about hepatitis C, in response to comments about and individual with this infection in the home for people from Eastern Europe. The questions revolved around the transmissibility of STDs.
- There was a discussion of the routes of transmission of different hepatitis infections.
- Participants’ comments included, "we now know more", "I will be more careful", "we are more protected", "we expose ourselves less to risk".
- One participant mentioned that since participating in the study, her behaviour was generally more cautious, for example, at parties she would avoid touching individuals who had cuts or other wounds.
- A participant asked if hepatitis can be transmitted through heterosexual activity.
- Asked about their mental image of hepatitis, participants comments included the following: "it could be a bug that eats someone on the inside", "liver", "a disgusting, terrible, slow death", "If a person is infected I try to get away from them, otherwise I will catch it", "see many devils"; they mentioned that they feel more protected with more care, and have lower risk.
- When asked what they knew about hepatitis, they responded with more questions about their symptoms and about transmission of the infection; one participant
started to explain her understanding to the other, and her comments were corrected and reinforced by the moderator.

Aim 5
[To gather proposals for implementing a screening system among immigrant groups]

- Asked about the recommendation to screen people from their native country, participants mentioned that many people have this infection but don’t know about it
- One participant explained that he met a family who have it but don’t know how to access the health system
- One participant said "we all know that hepatitis A occurs in children and is very contagious", an assertion corroborated by others. They stated that "we are not afraid because we know that it is a routine disease like chicken pox"
- It was mentioned by one participant that this infection is common in "poor countries where it is associated with drug use, shared syringes, and unemployed young people"

- In relation to the perception of the most important health problems in their communities, participants indicated cancer, cardiovascular diseases, and alcohol use. One participant said that men create more health problems in general
- It was noted that that hepatitis C is very expensive to cure and takes a long time, and that people in their country of origin cannot afford this
- It was emphasized that people don’t know whether they have it, and that analysis are not requested because they are very expensive
- Only people who are seriously affected go to the doctor, but these cases cannot be cured because they arrive very late
- It was mentioned that there is no culture of going to the doctor. There were also comments about how difficult it is to find a good doctor
- One participant said that healthcare was more organised in the time of the USSR, but that now services often have to be paid for on the black market; she gave the example of cataracts, which cost €600 in Armenia, but are free here
- A participant mentioned that in their country of origin their parents and grandparents had made important sacrifices, but that this had not translated into better social services for the current generation, whereas in Spain this had been the case
- In general, there is a perception that people in these communities would participate in projects such as HEPscreen.
- Some participants suggest that in order to contact individuals from the target population, we should go to places where these communities gather, such as shops and cultural events, and provide information about the importance of health so that people will disseminate the message
- A participant mentioned that they "know many people who have it, but who maintain it in private", in which case "it is difficult to go to the doctor"
- There is a perception that people with hepatitis feel discomfort, are stigmatized, and who become isolated as a result.
- One participant said that people in their communities who have hepatitis are rejected
In relation to the incentives to participate in a screening study, participants mentioned they liked the el Corte Inglés card. Some say they would prefer cash, but did not specify the amount, while others found it difficult to respond; Some mentioned that it is currently difficult to go to the doctor because of problems with the health insurance card and not feel that is a priority; Barcelona is perceived as a context that offers better possibilities for health; There was a discussion about the health insurance card and the different levels of coverage; some participants said that they had learned about the differences between hepatitis B and; Participants began to talk about vaccines; It was noted that there is much fear of AIDS, but that people with hepatitis live also with serious problems; One participant mentioned that while AIDS produces great fear, but that hepatitis is “nothing in comparison”; Participants added that almost all drug injectors have hepatitis and know about it, and questioned this behaviour in people who are aware of being infected; Finally, it was mentioned that some people don’t know that hepatitis is as dangerous as AIDS.

Results of "sticker voting"

<table>
<thead>
<tr>
<th>Statements</th>
<th>Very bad</th>
<th>Bad</th>
<th>Regular</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you assess the educational session in general? (Includes location, timing, language, CHW attitude ...)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How would you assess what you learned about hepatitis during the educational session?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. What did you think of the access to the different medical visits?</td>
<td>1</td>
<td></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. What do you think of a metro card as an incentive to participate in the study?</td>
<td></td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. What did you think of the attitude of the health staff during the various appointments?</td>
<td></td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. What did you think about how they explained the different issues related to the study during the various appointments? (including topics related to hepatitis, tests, vaccines, etc.)</td>
<td></td>
<td>1</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. What do you think of the knowledge gained about hepatitis after having taken part into the study?</td>
<td></td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. How do you feel that this study has contributed to your attitude about hepatitis?</td>
<td></td>
<td>1</td>
<td>6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Observations

- Everyone showed a positive attitude and was very participatory.
- Two women participated in the study because they were contacted as cultural mediators.
- It was occasionally necessary for the cultural mediator to intervene, especially with four participants.
- The cultural mediator made useful comments and offered support in several instances.
- The participants were very interested in hepatitis transmission and preventive measures.
- They expressed concerns about how to access the health care system if you encounter a person with hepatitis.
- The sticker voting results show that there was difficulty in accessing health services, which was not clearly expressed in the FG.
- Stigmatisation appears to be a key factor that hinders screening among people from these countries.

4.5.3 Interview with Romanian people

Date: 11th July 2014

Location: The session took place in a meeting room at Barcelona Public Health Agency, near the Health Service.

Duration: 40 minutes, plus 15 minutes for refreshments

Moderator: Constanza Jacques

Observer and Camera Operator: Sandra Manzanares

Cultural mediator: Carmen Estanescu

We intended to carry out an FG on Friday 27/06/2014, for which only 3 people confirmed their attendance, so the meeting was suspended. It was convened for a second time on 11/07/2014, for people from Romania and also from Eastern Europe, but many could not be contacted (telephone number invalid in most cases). Six individuals confirmed that they would participate, but ultimately only two attended. Since the criteria for conducting a focus group were not met, the research team decided to conduct a short interview with these participants, guided by the objectives of the FG and thus taking advantage of their presence at ASPB.
### Participants:

<table>
<thead>
<tr>
<th>Nº</th>
<th>Sex</th>
<th>Place of birth</th>
<th>Year of arrival</th>
<th>Age</th>
<th>Health Card</th>
<th>Residence Permit</th>
<th>Educational level</th>
</tr>
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<td>Yes</td>
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<td>2</td>
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<td>Romania</td>
<td>2009</td>
<td>23</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
</tbody>
</table>

**Female, 23 years old.**

- She explained that a Catalan friend saw an interview on TV with a Romanian mediator of an international health unit, and so contacted the unit to discuss joining the study.
- She had a good perception of the transport card as an incentive, but said that she would also have participated without an incentive.
- She said that she had a positive experience in dealing with health staff.
- She did not remember having participated in any ES.
- She did not remember that they had asked intimate questions during the visit with the doctor.
- She said that had little prior knowledge of hepatitis, and associated it with sexual transmission, or with children and vaccination.
- Asked about encouraging people in her community to participate in a screening study, she said it was important, that many people unknowingly have the infection and only become aware when it is too late.
- Among the perceived most important health problems in her country: cancer, hepatitis.
- She perceived that the biggest advantage of having participated in the study is the link created with the health care system.
- She said that the people of Romania are not usually aware of health problems.
- She showed concerns about the processing of the health insurance card.
- She said that she recommended participation to people she knows, but considered that Romanians did not perceive hepatitis as a health problem.
- She stated that people are afraid to ask about these issues because of other people’s prejudices.

**Male, 47 years old**

- He mentioned that he was approached outside a church after mass, and that this is a place he regularly visits. However, he did not remember having attended the ES, just that they gave him some information.
- He participated willingly, and did not remember that they offered an incentive.
- He said that his dealings with health personnel was very positive.
- He said that he had participated in a course on hepatitis in Romania.
- He identified hepatitis as an STD.
- He considered that hepatitis is a problem in Romania, and around the world, and associated it with self-care and hygiene.
- Asked about what he perceived as the most important health problem in his country, he responded lying, stealing, rage, corruption, and then chemicals in food.
- He believes that people are well informed about hepatitis, and that those who know him do not share information even for economic interest. He said that it should not be embarrassing to talk about this issue.
- He believes that while people consider it shameful to have AIDS or other sexual transmitted diseases what is really shameful is not health status, but rather not informing others if you know that you have and infection, or if you have information about it.
- He said that social status can influence not saying that you have hepatitis because the lower your social class, the more discrimination you are subject to.
- He said that people should help others so that this does not happen.
- He said that people from Romania would not agree to testing because they are much less motivated.
- He suggested that it be the church itself that proposes participation in this type of study, especially the priest, since people trust him.

Results of "sticker voting"

<table>
<thead>
<tr>
<th>Statements</th>
<th>Very bad</th>
<th>Bad</th>
<th>Regular</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.- How would you assess the educational session in general? (Includes location, timing, language, CHW attitude ...)</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>2.- How would you assess what you learned about hepatitis during the educational session?</td>
<td></td>
<td></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.- What did you think of the access to the different medical visits?</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>4.- What do you think of a metro card as an incentive to participate in the study?</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>5.- What did you think of the attitude of the health staff during the various appointments?</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>6.- What did you think about how they explained the different issues related to the study during the various appointments? (including topics related to hepatitis, tests, vaccines, etc.)</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>7.- What do you think of the knowledge gained about hepatitis after having taken part into the study?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.- How do you feel that this study has contributed to your attitude about hepatitis?</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>9.- What do you think of the possibility of hepatitis testing in people from your country?</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Observations

- Both participants were with very willing and participatory in answering the questions
- Both participants mentioned that they had little or no recollection of the various steps of the project (attendance at the educational sessions, receipt of the incentive). We were doubtful of these affirmations, and sought verification. We verified that they had signed the proof of their attendance at the ES and of having received the incentive.
- The second attempt and failure to carry out an FG with people from Romania was a new observation that emerged in the interviews.
- The cultural mediator for this population group raised our awareness of the mistrust that Romanians have towards any form of control (whether health, legal, etc.).
- Both the cultural mediator and the participants emphasized the importance of corruption in the health system in Romania
- Participants emphasized the importance of corruption in the health system in Romania

4.5.4 Focus group with Latin Americans

Date: 22nd July 2014

Location: The session took place in a meeting room at Barcelona Public Health Agency

Duration: 90 minutes, plus 15 minutes for refreshments

Moderator: Constanza Jacques
Observer: Manuel Fernández
Camera Operator: Marta Arcas

Participants:

<table>
<thead>
<tr>
<th>N°</th>
<th>Sex</th>
<th>Place of birth</th>
<th>Year of arrival</th>
<th>Age</th>
<th>Health Card</th>
<th>Residence Permit</th>
<th>Educational level</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>Ecuador</td>
<td>2009</td>
<td>47</td>
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<td>Yes</td>
<td>Secondary</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>Bolivia</td>
<td>2006</td>
<td>51</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>Bolivia</td>
<td>2006</td>
<td>51</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>Colombia</td>
<td>2000</td>
<td>69</td>
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<td>Yes</td>
<td>No studies</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>Chile</td>
<td>2007</td>
<td>63</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>Ecuador</td>
<td>2000</td>
<td>53</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>Ecuador</td>
<td>2002</td>
<td>63</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>Colombia</td>
<td>2004</td>
<td>49</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
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<tr>
<td>9</td>
<td>F</td>
<td>Peru</td>
<td>2002</td>
<td>57</td>
<td>Yes</td>
<td>Yes</td>
<td>Secondary</td>
</tr>
</tbody>
</table>
The main responses regarding the aims were as follows:

Aim 1

[To evaluate aspects of the Educational Sessions (ES) carried out by Community Health Workers (CHW)]

- Participants said that the found the ES interesting and liked the videos
- It was mentioned that they did not remember the content of the sessions
- Some participants found out about the ES through associations, NGO’s or religious centres that they regularly attend
- One participant said that they contacted him via his consulate, and invited him to participate in a study of Chagas Disease; he was informed about the HEPscreen project by the International Health Unit
- There were no accessibility problems because everyone knew the locations where the educational sessions would be held
- Participants mentioned that their motivation for participating was to find out about their health status
- A Peruvian woman said that her daughter had had hepatitis A and had been very ill, so she was interested in attending the ES because she had doubts and wanted to learn more about this disease
- Another woman said she participated because she works in a residence for elderly people and wanted to know if she was infected.
- One participant said they were motivated by the transport card incentive
- Participants mentioned that they would like to know the difference between hepatitis A, B and C
- Participants perceived that they had learned something in the educational sessions
- They said that before participating in the study they did not know what hepatitis was, the routes of transmission, or the symptoms, but that they had heard something about it, for example that the sufferer becomes yellow, and that there are different types.

Aim 2

[To gauge perception of accessibility to participate in the different phases of the study]

- Participants mentioned that it took approximately one month between the educational sessions and the visit with the doctor
- There was no difficulty in accessing the health centre
- Their treatment by administrative staff was perceived as positive, both during phone calls and in terms of personal attention at the health centre
- The transport card was seen as a good incentive for participating in the study
- One participant said that they had participated without incentive, because they wanted to take advantage of the opportunity to know more about their health
- A Bolivian man began talking about Chagas Disease, saying that he went to the doctor because it was free, and that they had performed various tests
- In general, the participants said that they regularly visited the family doctor for check-ups
- Another Bolivian man returned to the subject of Chagas Disease, and said that he was very satisfied with the International Health Unit because their GP did not perform these tests
Aim 3
[To evaluate aspects of the visits and the health care received (counselling, understanding the study, diseases, etc.)]

- All participants mentioned that they received very good treatment and attention from the doctors. They said that neither hepatitis nor the project was discussed during their visit with the doctor, and they did not perceive it as a necessity.
- The Bolivians mentioned that Chagas Disease is an important disease in Andean countries and began to talk about the mode of transmission, the insect vector, where he lives, and its prevalence in his family.
- Another issue that was considered important was malaria and the insect that transmits it.
- One participant explained that he had commented that he had a pain in the area of lower back pain and that the doctor performed a bypass, perceived with great satisfaction.
- Half of the participants recalled that they had answered questions related to HEPscreen survey, but that they felt uncomfortable about this.

Aim 4
[To gauge perception of aspects of hepatitis (risks, fears, care, etc.)]

- Participants mentioned that having participated in the project had not caused a change in their behaviour in relation to prevention of hepatitis.
- Participants mentioned that as a result of the study they had begun the process of vaccination against hepatitis viral.
- They began to talk about the cost of vaccination and the cost of treatment.
- The moderator asked about how hepatitis is transmitted, and the first response was that it is transmitted by sharing syringes. Then there was a moment of silence and the respondent said that they did not remember very well. The participants spoke about transmission through food and coughing.
- In relation to the mental image associated with talking about hepatitis, the mentioned the following: “fright”, “dangerous”, “cirrhosis”, “liver”, “contagious”, “treat it as soon as possible”, “it’s like cancer, if you don’t know that you have it and do nothing to treat it, it becomes more advanced”.
- One participant said that they don't usually talk about hepatitis in their social circle. One woman said that she would like to people from her social group to participate in the study.
- One participant said that they had received a leaflet from a member of his family.
- At the meeting stated that "if not one can die"
- One participant said that since it is free, participation in this project is a privilege that not everyone can afford otherwise.
Aim 5
[To gather proposals for implementing a screening system among immigrant groups]

- According to the participants, the most important diseases in their countries are: AIDS, infectious diseases due to lack of hygiene, polluting products, hepatitis and cancer. They placed considerable emphasis on cancer
- They said that in their countries there are no campaigns that provide information on dangerous diseases and people are not invited for free testing
- Participants have the perception that people in their community would participate in this type of study
- There was greater difficulty in participating in a study that requires so many visits, especially for work or economic reasons.
- One participant said that you have to “give culture” to people and “that participating is quality of life”
- Suggestions for encouraging the immigrant population to undergo screening were as follows: associations, consulates, through councils (participants said that it would not bother them if they were called to participate), and the church
- In relation to the type of incentive that should be offered, opinion was divided. Some said that they would participate simply because of the fact that medical care is free of charge, and because of their curiosity about the state of their health.
- One participant proposed the possibility of having access to the results of the study, and thus have feedback on this process
- Participants asked about the routes of transmission of hepatitis, and the moderator gave a short review on the most relevant aspects of this infection.

Results "sticker voting"

<table>
<thead>
<tr>
<th>Statements</th>
<th>Very bad</th>
<th>Bad</th>
<th>Regular</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you assess the educational session in general? (Includes location, timing, language, CHW attitude ...)</td>
<td></td>
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<td>4</td>
</tr>
<tr>
<td>2. How would you assess what you learned about hepatitis during the educational session?</td>
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<tr>
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</tr>
<tr>
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<td></td>
<td>9</td>
</tr>
<tr>
<td>6. What did you think about how they explained the different issues related to the study during the various appointments? (including topics related to hepatitis, tests, vaccines, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>
Observations

- It was a very participatory group, were concerned about for their health and that of their community.
- There were some contradictions between their perception of what they learned and what they actually learned. Participants positively valued the educational sessions, but they had difficulty in responding to questions about hepatitis.
- Participants tended to respond affirmatively to the questions, often repeated the comments of the other attendants, and there was little difference of opinion.
- Participants said that they would be willing to participate in other sessions or screening studies. It is unclear if that will has the ability to access to health care or the incentives that are delivered.
- The men participated more than the women.

4.6 Conclusions

In relation to the general aim, this group gave a positive evaluation of the project. The people who participated in all stages of the study represent a specific profile that tends to be motivated to know and care more about their health status, which clearly influences the results of our study.

The educational sessions were highly valued, as was the relationship with the CHW. However, while participants perceived that they had learned a lot during the ES, the FGs revealed many persistent doubts and served as an excellent opportunity to review and comment on basic concepts regarding transmission routes, symptoms, etc.

Participants also appreciated of having received a free service and an incentive. Those who did not have a health insurance card very much appreciated participating in the study, in part because it offered them free screening for hepatitis, but especially because it allowed them to gain access to the public health system. The time that they had to wait between the ES and the first visit with the GP was also an important factor for participation in the project.

The participants in the FG compared the health systems in Spain and their home countries, and highly valued the possibility of accessing medical and prevention programs. They
perceived that this type of screening strategy does not exist in their countries, and that the healthcare system in general does not provide adequate care for the citizens.

The treatment offered by the healthcare professionals during the different stages of the project was highly valued. Although they mentioned that they did not receive information about hepatitis nor about the project, this was not perceived as necessary or relevant. There were some communication problems among people from CEE countries who did not speak Spanish or Catalan, and a lack of cultural mediators made it more difficult to offer adequate counseling, which may have influenced their responses to the questionnaire.

It is important to consider that individuals from the target populations perceive health problems to be a priority. This allows us to identify their concerns regarding certain diseases, and the factors that motivate their participation in screening studies. People from Latin America often associate hepatitis with childhood illness or vaccination, while people from Eastern Europe associate it with drug use, and as a stigmatised disease. It is important to take this view of hepatitis into account when designing screening campaigns.

The main differences between the perceptions of individuals from LA and CEE countries regarding hepatitis can be summarised as follows:

<table>
<thead>
<tr>
<th>Latin Americans</th>
<th>Central and Eastern Europeans</th>
</tr>
</thead>
<tbody>
<tr>
<td>These communities do not generally perceive a risk of hepatitis infection.</td>
<td>There is often a perception of risk, and this is usually with socially marginal groups (e.g., intravenous drug users).</td>
</tr>
<tr>
<td>Hepatitis is related to childhood illness, and is not considered to create significant health problems in the population.</td>
<td>Hepatitis is perceived to be a stigmatised disease, which inhibits people from undergoing screening.</td>
</tr>
<tr>
<td>It is associated with vaccination.</td>
<td>There is a perception that hepatitis treatment is not free in the country of origin, so people with economic problems do not access the health system.</td>
</tr>
<tr>
<td>The health problems that are perceived as most important in these groups were: HIV/AIDS, syphilis, cancer, Chagas Disease and sexually transmitted infections.</td>
<td>The health problems that are perceived as most important in these groups were: cancer, cardiovascular diseases, hepatitis and alcoholism.</td>
</tr>
</tbody>
</table>

Although it was generally positively perceived that people from these countries participate in screening programs, there was no consensus on the need to provide an incentive. While some mentioned that it was not necessary to provide any financial or material compensation, others felt that it was essential. Contacting people from these communities at common meeting places such as parties, churches, etc. was viewed positively.
It was mentioned that the social and economic vulnerability of some immigrant groups conditions their participation in screening programs, often in relation to work, legal and administrative status, etc. In these cases, visiting the doctor when one does not have symptoms is considered a distant priority.

The “sticker voting” activity was very positive, and allowed participants to respond with greater anonymity than in the discussion session, in that they would not be as strongly influenced by the rest of the participants. The results of this activity indicated that participants perception of their involvement in this project was positive, whereas their perception of the extent to which other people from their country would participate in this type of program tended to be lower. This leads us to reflect on the perception of risk that individuals from these communities might have, and their motivations for participating in screening programs depending on the disease in question.

4.7 **Recommendations**

- For future screening projects, it is very important to consider immigrants’ perception of the disease in question, and their experiences with the health care systems in their home countries.

- It is advisable to propose screening strategies that are shorter or require less time from the participants. One possibility would be to perform hepatitis testing and data collection in the same place as where educational sessions are held.

- It is important to have access to cultural mediators for people who have little knowledge of the language of the destination country, to obtain a good medical history, and to enquire about possible risk factors.

- It is interesting to emphasize learning strategies are adapted to each community and social class in each stage of the process.
Comprobante de recibo de incentivo

**GRUPO FOCAL DEL PROYECTO HEPSCREEN: CRIBADO DE HEPATITIS B y C EN POBLACIÓN INMIGRANTE**

Yo, (nombre y apellido)..............................................................................................................................

... he recibido una tarjeta del Corte Inglés equivalente a 30 euros como incentivo por la participación voluntaria en un grupo focal dentro del Proyecto HEPscreen: Cribado de hepatitis B y C en población inmigrante, que se desarrolla por el Servei d’Epidemiologia Clínica de l’Agència de Salut Pública de Barcelona

*Fecha y firma*
CONTRATO DE CESIÓN DE DERECHOS DE IMAGEN

En Barcelona a ___ ____________ de 2014

Yo D. ______________________________ con DNI/N.I.E. n.º: ______________, como participante del Proyecto HEPscreen (cribado de hepatitis B y C en población inmigrante) que se desarrolla en el Servei d’Epidemiologia Clínica de l’Agència de Salut Pública de Barcelona, doy mi autorización para ser filmado en una sesión dentro del ámbito del mismo proyecto y con finalidad científica. En ningún caso estas grabaciones serán difundidas por medios públicos (TV y similares).

Mi autorización se refiere a la totalidad del uso que puedan tener las imágenes, o parte de las mismas, en las que aparezco, utilizando los medios técnicos conocidos en la actualidad o que pudieran desarrollarse en el futuro, y para cualquier aplicación. Todo ello con la única salvedad y limitación de aquellas utilizaciones o aplicaciones que pudieran atentar al derecho al honor en los términos previstos en la Ley Orgánica 1/85, de 5 de Mayo, de Protección Civil al Derecho al Honor, la Intimidad Personal y familiar y a la Propia Imagen.

Mi autorización no fija límite de tiempo para la concesión ni la explotación de las imágenes, o parte de las mismas, por lo que mi autorización se considera concedida por un plazo de tiempo ilimitado.

Firma del participante

Fdo._____________________________
Dovada de primire de stimulare

GRUP FOCAL AL PROIECTULUI HEPSCREEN: CONTROLUL HEPATITEI B I C IN CADRUL POPULAIEI IMIGRANTE

Eu, (nume si prenume)..............................................................................................................................

Eu, (numele i apellido)..............................................................................................................................

Am primit un card Corte Inglés, echivalentul a 30 de euro, ca un stimulent pentru participarea voluntară într-un grup focal în cadrul proiectului HEPscreen: controlul hepatitei B i C, în populaia imigrantă, care s-a desfasurat în cadrul Serviciului de Epidemiologie Clinica catalană a Ageniei de Sanatate Publica din Barcelona

Data

Semnatura
ACORD DE CEDARE A DREPTURILOR DE IMAGINE

În Barcelona în __iunie 2014__

Eu ______________________________ cu NIE : ______________ ca și participant în Proiectul HEPscreen (screening-ul hepatitei B și C în rândul imigranților), care se desfășoară în cadrul Serviciului de Epidemiologie Clinica din cadrul Agentiei de Sanatate Publica din Barcelona, autorizez să fiu filmată într-o sesiune de grup care se realizează în interesul aceluiși proiect și în scopuri științifice. În nici un caz, aceste înregistrări nu vor fi difuzate de mass-media publică (TV și altele asemenea).

Autorizația mea se referă la totală utilitate care se poate acorda imaginii în care eu apar, sau o parte a acesteia, folosind mijloace tehnice cunoscute acum sau care se pot dezvolta în viitor, precum și pentru orice altă (ț) aplicare. Excepție fac acele utilizări sau aplicații care ar putea submina dreptul de a onora termenele prevăzute în Legea organică 1/85 din 05 mai, de protecție a dreptului civil la onoare și intimitate personală și de familie, de confidențialitate și imagine de sine.

Autorizația mea nu stabilește nici o limită de timp pentru concesionarea sau exploatarea imaginilor, sau o parte a acesteia, astfel că se consideră acordată pentru o perioadă nelimitată de timp.

Semnatura participantului

Fdo. ______________________________
КОНТРАКТ НА УСТУПКУ ПРАВ НА ИЗОБРАЖЕНИЯ

Барселона, __ июня 2014

Я ____________________________, N.I.E. п.º: ____________, в качестве участника проекта HEPscreen (выявление гепатита B и C среди иммигрантов), который осуществляется Службой клинической эпидemiологии Агенства общественного здоровья Барселоны (Servei d'Epidemiologia Clínica de l'Agència de Salut Pública de Barcelona), даю согласие на съемку фокус-группы в рамках указанного проекта в научных целях. Эти записи ни в коем случае не будут распространяться по каналам средств массовой информации (телевидения и т.п.).

Мое согласие касается использования в полном объеме или частично записанных кадров, в которых я присутствую, при помощи как современных технических средств, так и тех средств, которые могут возникнуть в будущем, для любого использования. Все сказанное справедливо, за единственным исключением тех форм использования, которые могут нарушить честь в понимании, предусмотренном Органическим Законом 1/85 от 5 мая «О гражданской защите права на честь, на невторжение в личную и семейную жизнь и на личные изображения»

Мое согласие на уступку и использование записей или их частей не имеет временного ограничения, и, таким образом, мое согласие считается действующим неопределенный срок.

Подпись участника

____________________________
Appendix V – Example of “Sticker voting” in Spanish

<table>
<thead>
<tr>
<th>Cómo evaluarías la sesión Educativa en general?</th>
<th>Muy malo</th>
<th>Malo</th>
<th>Regular</th>
<th>Bueno</th>
<th>Muy bueno</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incluye lugar, hora de realización, actitud del mediador.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cómo evaluarías lo que has aprendido sobre las hepatitis durante la sesión Educativa?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

- Rojo: Muy malo
- Azul: Malo
- Amarillo: Regular
- Verde: Bueno
- Verde claro: Muy bueno
Appendix VI – Photographs of the focus groups

- Focus group with Central and Eastern Europeans

- Focus group with Latin Americans