

Participant Information Sheet

MOTIVATE-C

The Methodical evaluation and Optimisation of Targeted IncentiVes for Accessing Treatment of Early-stage hepatitis C

You are invited to take part in this study as you have self-identified as having hep C. You are provided with this information because it is important for you to understand why the research is being done and what is involved before you decide to take part in this project.

Please take time to read the following information carefully and, if you wish, discuss it with friends, relatives, or anyone who provides your health support. You will be assigned a trained treatment navigator who will help you access testing and treatment. The navigator will go through this information with you and answer any questions you have about the project. When all your questions have been answered, you can decide if you want to take part in this project or not. Taking part in this project is completely voluntary.

What is this project about?

We want more people with hepatitis C infection (hep C) to access treatment through their primary care provider or General Practitioner (GP).

Treatment of hep C is important because it helps stop liver damage and might prevent liver cancer. Current medicines to treat hep C are safe, very effective, easy to take with as little as one tablet a day, and available at low cost for people who have a Medicare Card because they are subsidised by the Australian government. Current medicines are very different from older treatments which often gave side-effects. These new hep C medicines cure most people (about 95%) from infection. Despite this, many Australians with hep C are yet to undertake the treatment and be cured.

Our project wants to find out how to encourage as many as people with hep C as possible to have treatment. In particular, we want to know if the offer of money incentives (payment rewards) enables some people to take up the treatment. This knowledge could change how hep C treatment is promoted.

How does the project work?

Participants are offered a compensatory payment of \$105 if they have a blood test to confirm their hep C infection and may be eligible to receive a money incentive if they commence hep C treatment. The payment/incentive is provided as a digital gift card or money loaded onto a physical debit card. Participants can use the money to help them cover out-of-pocket costs from having treatment, or they can use it for any other purpose they choose. While all participants are offered the compensatory payment, the money incentive may not be offered to all participants and among those who are offered the money incentive, not everyone is offered the same amount of money. This is because we want to work out if larger amounts work better than smaller amounts. The specific dollar value of the incentive you have been offered has been selected at random (like a roll of dice) by a computer. It is not controlled by your navigator and cannot be changed.

Your nominated primary care provider may also be eligible for an incentive amount.

What would we like you to do?

You will have to register your interest via an automated SMS-based registration system. Once you have registered and consented, the navigator will contact you and will ask you to:

- Provide information about yourself like your name, date of birth, mailing address (only if you request any project related documents to be mailed to you), whether you have a Medicare card, and what testing you have had for hep C in the past
- Tell us of important information that might affect your hep C treatment, such as medical issues, pregnancy, and any treatment for hep C you might have had in the past
- Provide us with the details of your preferred GP (if you have one). This process with the navigator should take around 20 minutes of your time.

Once the navigator has collected the information, the navigator will ask you to get a blood test to confirm that you have hep C infection currently and to get a prescription for hepatitis C treatment. This can be done through your preferred GP or, if you do not have one, the navigator can help connect you with a GP convenient to you.

The navigator will contact you after your appointment with the doctor so that you can show them the test result and the box of hep C medication prescribed to you. Once the navigator has confirmed the result of the test, they will release an electronic payment of \$105 to compensate you for your time. If you have been randomised to an incentive amount, the electronic payment to the value of your randomised incentive amount will be released once the navigator has confirmed that your hepatitis C prescription has been filled. You will be expected to get the prescription filled and commence treatment within 12 weeks of your enrolment in the study.

If your test result is not positive for hep C, you will not receive the randomised incentive amount. However, you will receive the compensation payment of \$105.

The navigator will contact you within 2 to 4 weeks following commencement of treatment to check on your progress and any issues you may have had in taking the treatment. On completion of treatment, the navigator will contact you to arrange another blood test (preferably 4 to 24 weeks after completion of treatment) to see if you have been cured of infection.

The navigator will record all the information you provide, including your test results for the project and researchers will use the information as explained in the section below 'What will happen to information about me?'

How will I receive my payment

You can choose to either have the payment as a digital debit/gift card (e-card) on your mobile device or elect to have the payments mailed to you as a physical debit/gift card. Note: if you choose to receive the payment via a physical debit/gift card, you will be asked to provide your mailing address.

There will be no merchant redemption restrictions on the Debit/Gift cards and there will be no Medicare, Tax and/or Pension implications.

Do I have to take part in the project?

Taking part is voluntary – it is your choice. Even if you decide to take part, you can change your mind later and withdraw from the project at any time, for any reason. This decision will not affect your ability to access hep C treatment or your future health care.

What are the possible benefits of taking part?

You will receive the help of a navigator to connect you to testing and treatment, and you may receive money incentive if you take part in the project. Also, by taking part in the project, we anticipate that you will be cured of hep c infection. Furthermore, we hope this project will help us find out how to get more people tested, treated, and cured of hep C.

Are there any risks, side effects, discomforts or inconveniences from taking part in the project?

While there isn't a risk of physical harm if you take part, we might discuss issues about your health or personal circumstances. If you find the discussions hard or distressful, you should let your navigator know as soon as possible. They will help you to access appropriate treatment or support.

What do I do if I wish to withdraw from the project?

You can withdraw from the project at any time. If you choose to withdraw from the project, we will not collect any new information from you. However, any information we have collected before you withdraw will be retained and included in the project results. This is to ensure our project findings are reliable and to comply with law.

What happens when the project ends?

If you would like a summary of our findings from this project, please let your navigator know.

What will happen to information about me?

If you provide consent, you will be agreeing to allow your navigator and others in the project team to collect and use personal information about you for the project. Any information that might identify you will be kept confidential.

We will provide your identifying information to a payment provider (iGODirect True Rewards <https://truerewards.com.au/>), only to administer payments to yourself in relation to the project. The payment provider will keep your identifiable information confidential.

Any collected information will be stored on a secure computer system protected by password; names and other information that could identify you will be kept separately. No one outside the project team will be able to connect you to your personal information. Contractual agreements will be in place with the third-party vendors (Twilio [sms-registration] and iGODirect True Rewards [the payment provider]) for the retention and disposal of your personal data.

We will store the information on the University of Sydney server for 15 years after the project is finished in case it is needed to answer questions about the project. After 15 years, all personal information related to this project will be destroyed.

We expect that the results of this project will be published or presented in a variety of ways. We will ensure that you cannot be personally identified in any publications or presentations.

Who is doing this project?

The University of Sydney is leading this project together with researchers, healthcare providers and experts within the hep C field. Funding for the project is provided by the Australian Government's Medical Research Future Fund.

Has this project been approved?

All studies in Australia involving humans are reviewed by an independent group of people with no involvement in the project called a "Human Research Ethics Committee" (HREC). The Sydney Local Health District Human Research Ethics Committee (2022/ETH01681) has reviewed the ethical aspects of this project and given approval for us to conduct this project.

If you have any concerns or complaints about this project, you can contact Sydney Local Health District Research Ethics and Governance Office, via email (SLHD-RPAEthics@health.nsw.gov.au) or telephone ([02 9515 6772](tel:0295156772)) on a confidential basis and quote protocol number X22-0287. Your concerns will be drawn to the attention of the Committee that is monitoring the project.

Who can I contact if I would like to know more information?

If you want to know more, please email the project team at motivatec.project@sydney.edu.au.

What happens next?

If you would like to take part, we will ask you to go through the consent form.