



EmERGE mHEALTH PLATFORM NEWSLETTER

EmERGE is a project funded by the European Union's Horizon 2020 Research and Innovation Programme under Grant agreement no: 643736.

EmERGE will develop a mHealth platform to enable self-management of HIV in patients with stable disease. The platform will build upon and integrate the existing mHealth solutions operated by pioneering healthcare providers in the UK and Spain and apply a rigorous co-design approach to ensure patient and clinician input to the solution.

The platform will provide users with web based and mobile device applications which interface securely with relevant medical data and facilitate remote access to key healthcare providers. EATG, the leading European HIV patient organisation, will provide a direct and deep interaction with representative patients and clinicians from 5 EU countries.

The platform and interfaces will be validated in a large study of 3900 patients using a tailored HTA process, MAST, specifically developed for the assessment of mHealth solutions including translatability as a key factor.



Project Leader Dr. Jenny Whetham talks about EmERGE

What do you think is the most exciting aspect of the EmERGE project?

Jenny Whetham: What's really exciting is the idea of being able to re-design and re-think the patient pathways, so that people who don't want to, don't need to come to clinic as often. Within our experience, the people that we care for in Brighton really love this. It's not for everybody, but it creates another option in the menu of care; that means people who have been living with HIV for a long time and are used to managing their care alongside having jobs, family lives and other commitments, don't need to go to the clinic as often. I think that the fact that we're doing this with novel technologies is also really exciting. Although there are a lot of health apps out there; I think what we are doing is slightly different as we're looking at integrating the app into the main hospital systems, but also doing it in a very robust way by creating a research project around it. This means we have a really strong co-designed socio-technical evaluation of the platform as we bring it in. We are also examining a number of other aspects including clinical outcomes, health economics, patient experiences, patient reported outcomes etc. So, I really think that this is a great opportunity for us to think about how to re-design our pathways, but also to

contribute to wider knowledge in terms of the impact of technologies in different settings.

Will you also extend the project to other disease areas than HIV?

JW: It's a really important part of the European Commission call that we are able to scale up, and to potentially market this as we go forward. We should be able to look at other disease areas and other settings. In the context of EmERGE we are essentially looking at people living with stable HIV, but one can actually see a role of such a platform for people living with more complex medical needs as well, be that within HIV or outside of that - there absolutely is an opportunity for that in the future.

Do you see any potential difficulties as you go along with the project?

JW: I think any study of this size is going to see challenges along the way, but we need to turn those into opportunities as we progress. There is a very technical side to the study in terms of making sure that we achieve complete technical integration and there are the other inevitable challenges associated with running a large research project. One of the great things, however, has been that we have a very strong consortium of collaborators who are continuing to have very transparent and open conversations and I think we're well equipped to face and overcome any challenges.

Where would you like to see EmERGE in five years from now?

JW: Within five years I would like to see a platform fully developed and integrated into our hospital systems with a clear plan as to how we are going to take that forward into other clinics and into other settings. Within this project, as you know, we have five clinical sites. But if this is something that is successful; something that patients like and want; if it helps us maintain and improve our level of clinical care within the HIV setting; if we get a positive response, then we'll make sure that it is available to other people and not just these five clinical sites that we are working in. In the next five years I would like to see a firm launching pad for taking this project forward into the future.

Do you have any key messages or comments to the readers of this newsletter, the stakeholders and participants of EmERGE?

JW: This first newsletter is really setting the scene: this is where we are, this is what our plans are; this is how we are hoping to take the project forward. I think my key point is that this is a really exciting, innovative project and a real opportunity to make changes that will reap benefits in the present and the future. In addition, I believe that there are many positive aspects that go beyond re-designing the patient pathways; we just have to make sure that we crack this and we get it right for all of our stakeholders, particularly for the patients who would be using the application.



In the early stage of the project, the **EmERGE study** is investigating whether mHealth provides a cost-effective alternative to frequent routine HIV outpatient clinic appointments for patients with well controlled stable HIV infection. Enhanced functions will be explored as part of the co-design process and offer the potential in patients to add to existing healthcare provision by improving interaction and information between different healthcare providers and so personalising HIV outpatient appointments with improved utilisation of multi-disciplinary teams.

EmERGE has 9 work packages:





Work Package 1 will perform a situational analysis and background assessment to inform the development of an mHealth platform in HIV - leading partner: Prins Leopold Instituut voor Tropische Geneeskunde (ITM)

It will:

- assess clinical settings and models of HIV care in clinical sites
- assess the ICT infrastructure and data security requirements in clinical sites and countries, and
- assess data already captured to assist the health economic analysis

The first task we imposed on ourselves was to get a detailed idea how people living with HIV currently are followed up in the five clinics that participate in the study. If we want to introduce a software application that makes the follow-up of stable patients easier, it is essential to know how it happens now. Various aspects were recognised: which activities at present guarantee the medical and psycho-social follow-up, which cadres are involved, which laboratory tests are done, which other investigations are possible, who pays for all of this... in short, we wanted to know how HIV care is organised. As we want to develop a software application, knowledge of the present information technology was equally crucial: what kind of (electronic?) patient file is used, how are data stored, how does communication with other health workers happen etc.

Detailed questionnaires were designed to capture all this information, covering ICT infrastructure and security requirements, HIV-care organization, information governance and the ethical-legal frameworks. These questionnaires were completed and discussed by the WP leaders and clinical leads on site.

All the results were written up and summarized in three reports. This information is and will be used not only to develop the application but also for the economical and socio-technical evaluation. In general, one could conclude that the content of the follow-up is similar at the five sites, but that there are striking differences in the way

care is organised. These differences are even more striking with regard to ICT infrastructure and ethico-legal frameworks. One common concern though was the protection of personal data of the patients and the desire to develop an application that helps the patient to live an even better life.



Work Package 2 - University of Brighton (UOB) will perform a socio technical evaluation of the EmERGE platform.

Between January and March this year Work package 2 has facilitated a co-design process where people living with HIV (PLWH) and clinicians have expressed their views concerning the design and components of the proposed mHealth application (App). Brian West and Ben Marent, who were involved in the data collection, had the great opportunity to visit all the five study sites: Brighton, Lisbon, Antwerp, Zagreb and Barcelona. With excellent support from community partners and lead clinicians at each site they were able to conduct a total of:

- 7 workshops with PLWH,
- 20 individual interviews with PLWH,
- 3 mixed workshop with PLWH and clinicians, and
- 3 workshops with clinicians

Through these methods we included 97 PLWH and 51 clinicians. Participants deliberated on the core functionalities of the proposed App and highlighted opportunities and concerns as well as other functionalities that could be useful for managing HIV. Summarizing our first impressions – we have not yet started with the data analysis – we can say that receiving results through an App is considered as relevant by many participants because it allows them to ‘own’ their medical data and have it easily accessible. PLWH also see an appointment management system (including reminders) through the app and information about prescribed medicines as useful functionalities that could make the management of their condition easier.

However, participants also explored a range of additional functionalities that would be useful for them, such as: a messaging system to ask questions to clinicians, a chat room with peers, a diary function (to take personal notes), a news section (that informs about new treatments) or traveling support (including e.g. the managing of medicines between time zones). Critical perspectives included issues around the confidentiality and security of the App and whether it will restrict the patients' access to face-to-face consultations with their HIV clinicians. An in-depth data analysis will be conducted within Work package 2 during the next months. Thanks to all community partners and clinicians that supported our research at each sites and made our stay in each city so enjoyable!



Work Package 2 - European AIDS Treatment Group (EATG) This year Benjamin Marent and Brian West participated in the community workshops held in Lisbon, Barcelona, Brighton, Antwerp and Zagreb. The workshops were well attended by a very good mix of people from the different communities affected by HIV. Some of the workshops also included both patients and clinicians.

The responses to the consultation on the development of the app were very constructive, informative, and on the whole pretty positive. Many were enthusiastic about the work to be done around the app. Comments were made about the benefits that it could bring. The concerns raised most often were related to the security of the app, the effect that it would have on the relationship with their clinics – in particular the reduction in personal contact with the HIV doctor. Another clear message was that the app needed to look innocuous – it could not scream HIV!

We would really like to thank our community partners for work they did here. They organised the workshops and selected the participants excellently. They were GAT – Portugal ; Projecte dels NOMS – Hispanosida; Lux Vitae – Croatia; Sensoa – Belgium and THT – UK.

The detailed work of analysing the responses will take place over the next few months, and this will feed into the app development. Thanks to everyone for their efforts. Great work – well done.



Work Package 3 will design and perform the collection of health economic data to enable the modelling and validation of the healthcare economics impact of the EmERGE mHealth platform - leading partner: The National Prospective Monitoring System (NPMS-HHC-CIC)

It will analyze the cost, cost-effectiveness and/or cost-savings associated with installing the mHealth platform in participating hospitals.

Using an agreed minimum dataset, the NPMS-HHC collects standardised data longitudinally and routinely in participating clinics from persons living with HIV using health services. NPMS-HHC has collaboration with a number of costing studies nationally within the UK and internationally.

So far, a description of pre- and post- intervention data has been completed and summarised, while a second report entitled ‘Report on completion of relevant costing data’ was also recently completed. The format of the routinely collected information, either electronic, paper or a combination of the two formats and the feasibility of

obtaining these data from the 5 clinical sites have been evaluated.

Data on pre-mHealth intervention can be obtained once the cohort of stable patients to participate in the EmERGE study has been identified. This will comprise the patients at each of the 5 clinical sites who will be followed-up prospectively. The final analyses will be performed towards the end of the study when the post-intervention data have been collected and analysed, and the pre- and post-intervention analyses on the use, cost and outcome can be compared.



Work Package 4 will focus on the platform development and deployment - leading partner: Podmedics (POD)

It will:

- gather technical requirements for the mHealth platform, with a particular focus on assessment and validation of individual site API requirements
- develop the platform using an agile approach that includes healthcare providers and patients.
- test the application platform and smartphone applications.



Work Package 5 will co-ordinate and manage the validation study of the EmERGE platform - leading partner: Fundació Clínic per a la Recerca Biomèdica (FCRB)
It will:

- develop protocol for validation study
- facilitate independent ethics committee submission at each study centre/ country
- respond as necessary to input from ethics committees
- monitor recruitment and adherence to protocol
- co-ordinate safety evaluation and study closure.

The WP is currently developing task 5.1: Protocol writing and ethics submission that will be finished at M16. (31st August 2016). The first deliverable 5.1 - Final Protocol completed for ethics submission to first ethics, will be finished at M12 (31st May 2016).

The first draft of the protocol has been completed, and the consortium members discussed it in much detail at a consortium meeting in Brighton, which looked at the various aspects with all stakeholders. After this, a final version will be produced and circulated for submission to ethical committees.



Work Package 6 coordinates the part on quantitative patient outcomes - leading partner: Brighton and Sussex University Hospitals NHS Trust (BSUHT)

It will:

- identify the optimal quantitative tools for evaluation of key outcome measures for use within the validation study
- validate these tools if not previously already undertaken in the setting of HIV infection
- identify HIV specific patient related outcome and experience measures (PROMs and PREMs) and to validate these within this programme of research in a pan-European setting
- Co-ordinate data analysis of the above and of clinical outcomes.

WP6 has been busy completing three systematic reviews – one looking at mHealth and HIV and the other two looking outcome measures in empowerment and health related quality of life in HIV. Empowerment and quality of life (QoL) are primary and secondary outcomes in the main validation study.

Depending on the findings in early WP2 co-design workshops and whether they are supported by patient and clinician groups, sub-studies had originally been proposed in adherence, pre-frailty and the measurement of HIV specific patient reported outcome and experience measures (PROM/PREMs). Work is ongoing to progress a framework for these.

The main work of the work package starts later with analysis of the data from the validation study and we are currently contributing to the protocol that is being written by our colleagues at FCRB. WP5 and WP6 are interwoven and we will continue to

work closely together throughout the project.



Work Package 7 will prepare for and enable the innovation and exploitation of the developed mHealth platform for HIV care - leading partner: mHealth Futures LTD (mHF)

It will:

- develop a sustainable business model for the provision of HIV mHealth services as a reimbursable cost by stimulation of innovation in healthcare providers.
- assess the mHealth platforms for commercial development and use in other chronic disease and health areas



The EmERGE project

Evaluating mHealth technology in HIV to improve Empowerment and healthcare utilisation: Research and innovation to Generate Evidence for personalised care.



Project leader and partners

- BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST (BSUHT) – UK
- UNIVERSITY OF SUSSEX (UOS) – UK
- EUROPEAN AIDS TREATMENT GROUP (EATG) - Germany
- UNIVERSITY OF BRIGHTON (UOB) – UK
- PRINS LEOPOLD INSTITUUT VOOR TROPISCHE GENESKUNDE (ITM) - Belgium
- PODMEDICS LIMITED (POD) - UK
- FUNDACIO PRIVADA CLINIC PER A LA RECERCA BIOMEDICA (FCRB) - Spain
- CENTRO HOSPITALAR DE LISBOA CENTRAL, EPE (CHLC) - Portugal
- KLINIKA ZA INFektivNE BOLESTI DR. FRAN MIHALJEVIC (KIB) - Croatia
- NPMS-HHC CIC (NPMS) - UK
- UNIVERSIDAD POLITECNICA DE MADRID (UPM) - Spain
- mHEALTH FUTURES LTD (MHF) - UK
- KITE INNOVATION (EUROPE) LTD (KITE) – UK

Web

www.emergeproject.eu



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mHealth technology in HIV to improve Empowerment and healthcare utilization.

Work Package 8 is the coordinator of the dissemination and popularization of the project - leading partner: European AIDS Treatment Group (EATG)

It will:

- establish a website for EmERGE serving internal and external communication to interested parties
- provide regular updates and sharing of good practice and opportunity for discussion by beneficiaries during the EmERGE programme
- disseminate study results to HIV patient community, the HIV scientific community and the mHealth technology communities.
- inform policy at national, European and wider international levels of the benefits of mHealth in HIV and potential extrapolation to other areas (geographical including developing countries, other chronic diseases).

In the initial stage of the project, the EATG set up a [Facebook page](#) to facilitate communication of project related information and a general discussion around the utility and importance of the use of mHealth for patient communities. The [EmERGE website](#) is another useful tool for the storage and dissemination of project related documents and news.

Regular newsletters like this first one will focus on key aspects of the project as it evolves.



Work Package 9

is leading the project management - leading partner: KITE Innovation Europe (Kite)

It will:

- optimise the management and communications environment in which the project is performed
- prioritise proactive communication and early identification and resolution of issues through open and effective communications with all stakeholders.



The EmERGE project was conceived by Professor Martin Fisher who invited an excellent, cohesive consortium from a range of disciplines to achieve the aims and objectives of this innovative project. EmERGE will be developing

and evaluating new pathways in HIV treatment and care across five clinical sites in Europe. Martin died unexpectedly in April 2015 and unfortunately wasn't able to see the start of the project. He leaves an amazing legacy and as a consortium we are committed to fulfilling his vision – and excited to be part of such a remarkable project.



Project partners



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