EmERGE

European AIDS Treatment Group

Implementation of mHealth in a country context
Croatia
community perspective

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When we started in 2016 and you googled **EmERGE** you got those answers:

1. EU project about efficient response to highly dangerous and emerging pathogens at EU level
2. Music Festival - the new kid on the festival block
3. The Italian Food Platform

Nothing about:

EU project about a mHealth platform to enable self-management of chronic disease

Co-design experience in Zagreb, Croatia

- EATG
- Local NGO
- Local community of PLHIV
- Clinicians

Good collaboration between the different actors

- PLHIV represented through EATG as partner in Consortium
- Local NGO Lux Vitae also members of EATG and good collaboration with clinicians
- Involved in the project since the beginning

- PLHIV consulted individually in design phase about app features and recruitment to study
- Workshops and interviews with researchers and clinicians in 2016, 2018 and 2019
- Co-design outcomes presented and discussed at annual community meetings with EATG and NGO partners from each study site

This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under Grant Agreement No. 643736

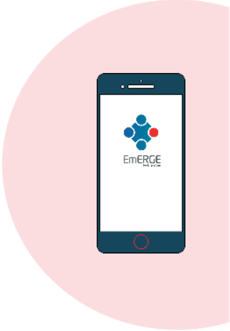
Darking M, et al. AIDS 2018. Poster THPED491; EmERGE newsletter - May 2018. Available from: https://www.emergeproject.eu/post/emerge-newsletter-may-2018 [Accessed November 2019]; EmERGE Community Meeting, June 2019. Available from: https://www.emergeproject.eu/post/emerge-community-meeting-june-2019 [Accessed November 2019]; EATG. Personal Communication

What we recognize to be **facilitators for implementation** of such a platform in Croatia?

- **Sense of ownership** - *“noting for us without us”, as partners in codesign patient opinions were integrated*
- **Engaging in process and decisions** – *opportunity to make change on time*
- **Added value** - *chance for networking and peer support*
- **Having a choice** - *patients consulted which functionalities they need in the app*
- **Being informed and disseminating information to others**

What we recognize as **possible issues** in Croatia that would prevent implementation of such a platform?

- **Stigma –** *afraid to be identified as being HIV- positive among peers and third parties*
- **Disclosure –** *afraid privacy could be breached*
- **Relationship with clinicians –** *if they have different opinions would they jeopardize this relationship*
- **Confidentiality and security –** *who will have access to their data and stories*

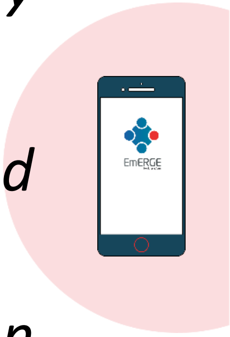


Fears mitigated - local community representatives being facilitator and transcribers of the co-design workshops

What were the benefits and drawbacks reported by community in Croatia for using the app?

What were the **benefit(s)** for using a mHealth App in Croatia?

- **Sence of ownership** of all health data regarding HIV in one place and the confidence to use them *(can be shared with other healthcare providers, friends, family e.g. to show they are doing well or to negotiate sexual relationships)*
- **Time and money savings** *(I don't have to take time off work and spend time traveling to clinic)*
- **Less uncertainty** *(allow me to see data important to my health and stay informed at any time)*
- **Activation and health behavior** *(motivate me and help stay engaged with my health)*
- **Avoiding stigma and preserving anonimity** *(less risk I will be seen going to the HIV clinic)*



What were the **drawbacks** for using a mHealth App in Croatia?

- **Security and privacy**

Even though it has codes and all kind of stuff…this app is online…Anybody can hack my email…I don’t want it to maybe one day, come out…if you say, “This app is here you can download it,”I will say:“No, thank you.” [P_Za_I]

- **Missing two-way communication and lacking health literacy** *(not having knowledge and skills to be able to interpret data)*

- **Relationship with clinicians, lacking personal interaction** *(“I value my relationship with my doctor and want to see them face-to-face”)*

- **Constantly confronted with their disease, becoming “obsesssed”**

I know myself and I know when I don’t feel good...Sometimes it’s better to ignore some things like that [medical data]. I mean you are living with the disease, but you don’t want to think about it every day. [P_Za_I, female]

- **Social Support**

[T]hey [clinicians] are not here at midnight...when you are scared and wake up in tears and shaking: “What do I do, oh my God, I´m HIV positive.” So I think that it will be a very good thing that you can go on the app and see someone online and only talk about HIV or about the weather... [P_Za_WSm, male]

Source: Marent et al, Development of an mHealth platform for HIV Care: Gathering User Perspectives Through Co-Design Workshops and Interviews, JMIR Mhealth Uhealth 2018;6(10):e184

Conclusion

- **Co-design enhance empowerment** by providing patients with the opportunity to engage as equal players in a process.
    - Patients indicated that they could voice their needs for the first time in a safe environment and they felt that they were heard.
    - Confidence to speak up about their needs, both from a clinical and technological perspective.
- **Important - EmERGE gives options** to suit health seeking behavior preferences (face to face vs technology) and do not replace patients access to clinicians.

What is important for users in the future?

- to **improve health literacy** among users of mHealth technologies, by embedding functionalities in the app and/or engaging with patient groups
- Implement mHealth interventions **taking into consideration local capacity,** as well as the needs and restrictions of local users (including issues related to HIV-related stigma and discrimination)

THANK YOU!!!

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