CASE STUDY: THE EMERGE PROJECT

Context

Many of the people that are living longer, healthier lives with HIV are keen to better understand the impact of HIV on their lives. As such, they want to be able to access their own health records. Ageing populations are with associated co-morbidities and complexities, creating the need for more efficient communication between people living with HIV (PLWHIV) and their healthcare providers.

EmERGE is a five-year Horizon 2020-funded project that is co-designing and evaluating a mHealth-supported pathway of care for those living with stable HIV.

Introduction

Innovation in healthcare delivery is needed to reflect the needs of the increasing numbers of patients successfully managing their HIV. PLWHIV may wish to choose to reduce their number of clinical visits. The number of clinic visits for PLWHIV stable on therapy (i.e. those with an undetectable viral load) has been decreasing in recent years. In some cases, this has been done in consultation with the community, but this is not always been the case. This study has been designed with built-in consultation of both PLWHIV and clinical staff as part of the process as well as an evaluation of any impact that a change to mHealth consultations may bring.

Aims

The overall aim of the EmERGE project is to assess the impact of a co-designed mHealth-supported pathway for people living with medically-stable HIV in diverse care settings in five European countries.

We report on facilitating the co-design process among PLWHIV and clinicians at the five clinical sites; Antwerp, Barcelona, Brighton, Lisbon and Zagreb - which had three aims at this stage:
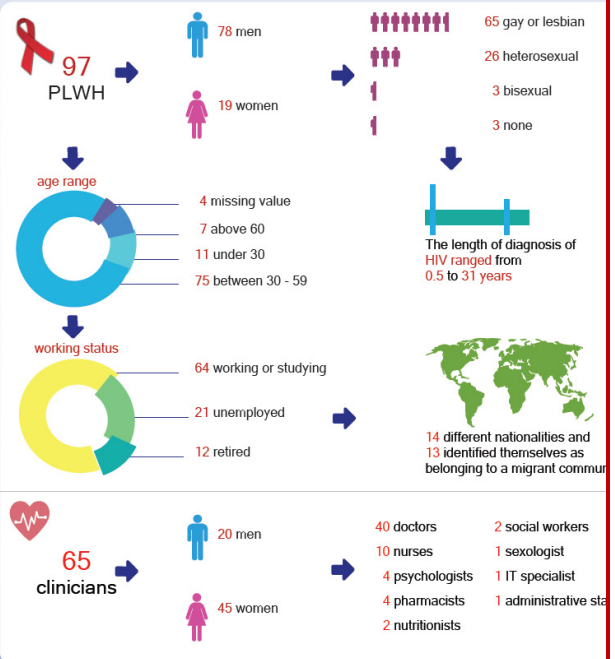1. *To elicit experiences of living with HIV and of working in HIV care;*
2. *To identify mHealth functionalities considered useful in HIV care;*
3. *To identify potential benefits as well as concerns over mHealth.*

HIVOutcomes
BEYOND VIRAL SUPPRESSION

Method

Methods:
Between January and June 2016, 14 co-design workshops and 22 semi-structured interviews were conducted involving 97 PLWH and 65 clinicians. Data were analysed thematically and iteratively, drawing on grounded theory techniques.

Study Site	Mode of data collection	Participants' gender Male PLWH	Participants' gender Male Clinicans	Participants' gender Female PLWH	Participants' gender Female Clinicans	Total nr. of participants PLWH	Total nr. of participants Clinicans
Brighton (Br)	1 Workshop PLWH	7		1		8	
	1 Workshop PLWH	6		3		9	
	2 Interviews PLWH	1		1		2	
	1 Workshop Clinicians		3		9		12
	1 Interview Clinicians				1		1
Lisbon (Li)	1 Workshop PLWH	4		4		8	
	1 Workshop PLWH	7		3		10	
	4 Interviews PLWH	4				4	
	1 Workshop Clinicians		2		11		13
	1 Interview Clinicians		1				1
Antwerp (An)	1 Workshop PLWH	9		1		10	
	1 Workshop (mixed)	5	1	1	2	6	3
	3 Interviews PLWH	3				3	
	1 Workshop Clinicians		5		9		14
Zagreb (ZA)	1 Workshop PLWH	5		2		7	
	1 Workshop (mixed)	3	2		2	3	4
	5 Interviews PLWH	4		1		5	
Barcelona (Ba)	1 Workshop PLWH	9		1		10	
	1 Workshop (mixed)	5	1	1	4	6	5
	6 Interviews PLWH	6				6	
	1 Workshop Clinicians		5		7		12
	7 Workshop PLWH 3 Workshop PLWH 20 Interviews PLWH 4 Workshop Clinicians 2 Workshop Clinicians	78	19	19	46	97 PLWH	65 Clinicans

97 PLWH
- 78 men
- 19 women

- 65 gay or lesbian
- 26 heterosexual
- 3 bisexual
- 3 none

age range
- 4 missing value
- 7 above 60
- 11 under 30
- 75 between 30 - 59

The length of diagnosis of HIV ranged from 0.5 to 31 years

working status
- 64 working or studying
- 21 unemployed
- 12 retired

14 different nationalities and 13 identified themselves as belonging to a migrant commun...

65 clinicians
- 20 men
- 45 women

- 40 doctors
- 10 nurses
- 4 psychologists
- 4 pharmacists
- 2 nutritionists
- 2 social workers
- 1 sexologist
- 1 IT specialist
- 1 administrative sta...

Results

Results:
Table 2 : Thematic Clusters and Categories

Approaching the mHealth Platform

Patients' Approaches	Clinicans' Approaches
• Re-negotiating stigma ? • New opportunities for control ?	• Compatibility and added value? • Who constitutes the target group?

Imagining the mHealth Platform

Medical Functionalities	Social Functionalities	General Features
• Accessing test results • Managing medicines • Managing appointments • Digital communications channels	• Peer-support network • International travel • Changing public attitudes towards HIV	• Security and privacy • Credibility • Language • Sensibility for disabilities • Costs • Training and tutorials • Other technicalities

Anticipating the mHealth Platform's Implications

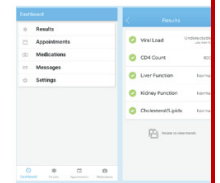| Implications for Self-Management	Implications for Healthcare Provision
• Creating (un)certainity? • Reconfiguring relations? • Altering the understanding of health?	• Replacing traditional care pathways? • Rationalities of mHealth? • Effects on workload?

The mHealth platform:
The EmERGE platform has been co-designed with patients and clinicians. It integrates into pre-existin... IT systems in place at clinical sites and consists of 2 applications

1. The Web application
Functionalities for clinicians: add a new patient, view 'virtual clinic' appointments and calendars, view and filter a list of all registered patients, send test results and messages

2. The mobile application
It consists of two compenents: An iPhone or Android application that is used by patients on their mobile devices and the Messaging Service that represents the Cloud Service used to relay messages securely from the Web Application to the patients' mobile device application

Functionalities for patients:
- blood test results,
- appointments,
- medication list + interactions,
- messages
- account information

Messaging service 256bit encryption No identiflable info SSL

Recommendations

- *Co-design with PLWHIV and clinical staff is an effective way to establish the needs of both service users and service providers, as well as identifying potential benefits and concerns.*
- *Co-design needs to be seen as a continuous process: once in use, platforms, apps and websites require constant 'fixes', 'updates' and 'versions' not only because of technological change but also as a result of sociocultural evolution.*
- *As the EmERGE mHealth platform is integrated in the local care pathways, we will investigate the technology in use, documenting the sociotechnical practices involved in engaging with, adapting and resisting mHealth.*
- *The EmERGE project is ongoing and will report in 2020. It includes evaluation of patient empowerment, quality of life, person-centred symptoms and concerns (using HIV-specific PROMs), quality of care and health economics alongside user experience and perspectives of PLWH and clinicians on this co-designed mHealth supported pathway of care.*

Authors: Mary Darking[1], Flis Henwood[1], Ben Marent[1], Brian West[2], Jenny Whetham[3] on behalf of the EmERGE Consortium.

Organisations:

1. University of Brighton

2. European AIDS Treatment Group

3. Brighton and Sussex University Hospitals NHS Trust

Date: 12/11/18

Email: Jennifer.Whetham@bsuh.nhs.uk

Phone Number: +44 1273 664731