

# Factors associated with Retention and Engagement in HIV care (the REACH survey)

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## BACKGROUND

- Life expectancy for successfully treated people living with HIV (PLWH) in the UK is similar to the general population
- People who engage poorly with care are at risk of poorer health outcomes and death
- Engaging people in HIV care remains a major challenge with little evidence on the factors to address

## AIM

The REACH project (Retention And Engagement in Care services for HIV positive patients in the UK) set out to explore, describe and understand patterns of HIV outpatient attendance in PLWH, in order to develop cost effective interventions to optimise engagement in care.

The study consists of three phases:

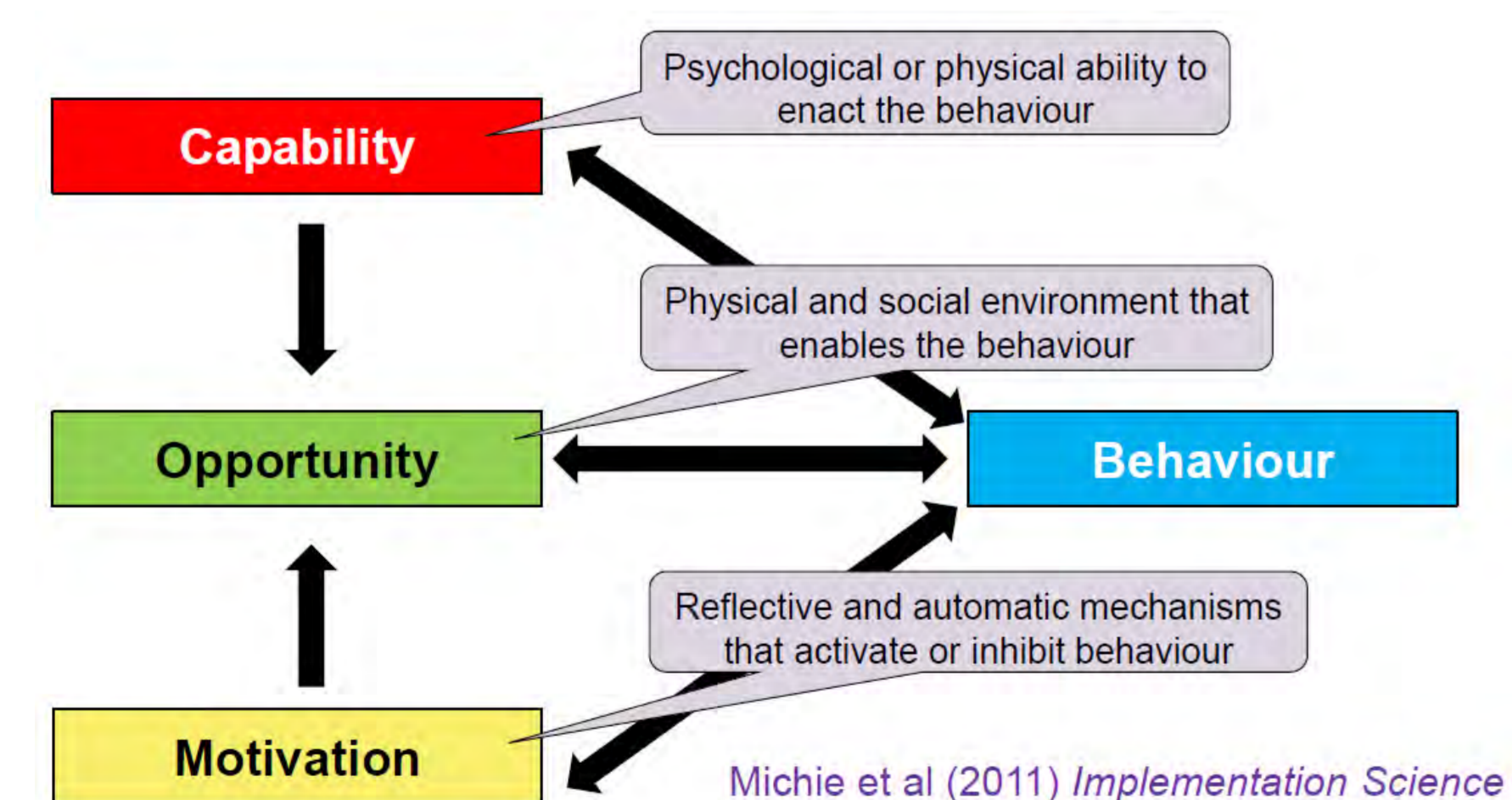
- PHASE 1:** analysis of routinely collected data from UK Collaborative HIV Cohort (UK CHIC) to determine health consequences and financial costs of disengaging from care
- PHASE 2:** collection of quantitative and qualitative primary data to explore patient experience of care at clinics to provide insights into factors which influence attendance of services
- PHASE 3:** interviews with key informants to explore barriers to engaging in care and service improvements

Here, we present an analysis of the quantitative data from PHASE 2 of REACH.

## METHODS

- Cross-sectional survey among patients attending 7 London HIV clinics (May 2014 – August 2015) (n = 983)
- Patients self-completed a pen-and-paper survey containing 80 questions
- Questions were selected to map onto the COM-B system (Figure 1) - which proposes that behaviour occurs as an interaction between three necessary conditions

Figure 1: The COM-B system



- Recruitment of:
  - 550 regular attenders (RA: all appointments attended in past year)
  - 269 irregular attenders (IA: 1+ appointments missed in past year)
  - 164 non-attenders (NA: attended in past year after absence of 1+year)
- Sample stratified to over-represent IA and NA
- No financial incentive for participation
- Chi square test to examine significant differences between proportions

## RESULTS

The associations between demographic, socio-economic and HIV-related factors and attendance pattern are shown in Table 1.

- Poorer attendance significantly associated ( $p < .05$ ) with being female, younger, heterosexual, not cohabitating, lower education, not being a homeowner, having moderate or severe hunger, being diagnosed for longer and not being on ART
- 2.3% of RA, 6.3% of IA and 6.3% of NA had missed appointments because of drinking alcohol
- 2.0% of RA, 13.0% of IA and 12.4% of NA had missed appointments because of taking drugs
- Patients with caring responsibilities sometimes or often missed appointments because of this (RA = 15.7%, IA=42.3%, NA=58.3%)

Patients were asked to report how often they had missed appointments since their HIV diagnosis for the reasons shown in Table 2.

- Only 60.7% of patients had never forgotten an appointment
- Key reasons for missed appointments (sometimes or often) were feeling depressed (21.2%), forgetting (20.5%), not wanting to think about being HIV positive (19.9%) or feeling too tired (19.0%)

Table 1: Factors associated with attendance pattern

Factor		All patients	RA	IA	NA	p value
Gender	Female	27.6	24.2	30.5	34.2	.02
	Male	72.4	75.8	69.5	65.8	
Age	<= 30 years	8.8	6.0	13.0	11.0	<.001
	31 – 45 years	44.0	40.7	46.1	51.2	
	>45 years	47.3	53.3	40.9	37.8	
Ethnic group	White	53.6	57.2	50.0	47.4	.138
	Black African	28.1	25.9	29.9	32.5	
	Other ethnic group	18.2	16.9	20.1	20.3	
Sexual orientation	Heterosexual	37.3	34.9	39.8	41.7	<.001
	Gay or bisexual	61.3	64.4	59.8	53.2	
	Other	1.4	0.8	0.4	5.1	
Born in UK		40.7	40.1	42.4	40.2	.812
English main language		79.9	78.5	82.5	80.3	.406
Cohabiting		34.2	37.6	30.2	29.2	.041
Caring responsibilities		25.0	22.6	26.7	30.2	.109
Working		58.9	60.8	56.5	56.3	.391
Education post-16 years	None	15.9	15.6	13.8	20.4	.037
	<= 2 years	13.9	11.5	16.1	18.4	
	> 3 years	70.2	72.9	70.1	61.2	
No religion		32.6	31.7	35.0	31.7	.630
Homeowner		27.9	33.3	22.1	19.1	<.001
Hunger scale	Little or no hunger	80.7	86.4	71.5	76.2	<.001
	Moderate or severe	19.3	13.6	28.5	23.8	
Years since diagnosis	<= 1 year	3.8	5.6	2.2	0.0	.002
	1-5 years	19.3	20.4	19.0	16.5	
	5-10 years	23.7	24.6	19.3	28.1	
	>10 years	53.2	49.5	59.5	55.5	
Currently taking ART	Yes	88.3	94.2	90.7	64.3	<.001
	No – but have done	4.4	0.9	4.5	15.9	
	No – never have	7.3	4.9	4.8	19.5	

Figure 2: Reasons for missed appointments: IAs compared to NAs



As RAs, by definition, were less likely to have missed appointments, we compared reasons given by IAs and NAs. Figure 2 shows the proportion of IAs and NAs who said they sometimes or often missed an appointment for the reason shown, divided up according to the conditions in the COM-B system.

- IAs were more likely to miss appointments because they felt too sick
- NAs were more likely to give reasons related to motivation

Table 2: Reasons for and frequency of missed appointments

Reason	Never	Rarely	Sometimes	Often
Forgot	60.7	18.8	16.2	4.3
Depressed	70.8	7.9	14.8	6.4
Too sick	71.1	12.7	14.1	2.1
Too tired	72.6	8.4	15.3	3.7
No time off work	75.1	10.3	9.2	5.4
Denial <sup>§</sup>	75.4	4.7	11.0	8.9
No money	77.6	7.5	11.1	3.9
Enough medication	80.5	4.9	8.0	6.6
Felt well	81.0	4.1	7.9	7.0
No transport	81.1	6.9	8.1	4.0
Afraid to be seen at clinic	84.7	3.7	7.4	4.2
Not followed doctor's advice	86.2	5.0	6.2	2.6
Doctor couldn't help	89.9	3.8	4.5	1.8

<sup>§</sup> The exact wording of this item was "Didn't want to think about being HIV positive"

## CONCLUSIONS

Engagement in HIV care is associated with demographic, socio-economic and HIV-related factors. Different patterns of attendance are also associated with multiple and particular underlying causes. Our findings suggest no one-size-fits-all method of improving engagement and support the use of a range of approaches to uncover and address these factors.