Identifying the PrEP Gap: An exploration of health equity in the HIV Pre-Exposure Prophylaxis Care Continuum

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PhD upgrade presentation
25th May 2021

Principal supervisor: Dr Lorraine McDonagh (PCPH)
Subsidiary supervisors: Professor Greta Rait, Dr John Saunders, Dr Hamish Mohammed

MRC Medical Research Council

Context

World Health Organization

38.0 million
People living with HIV

+ 24%
Relative to 2010

1.7 million
People newly infected

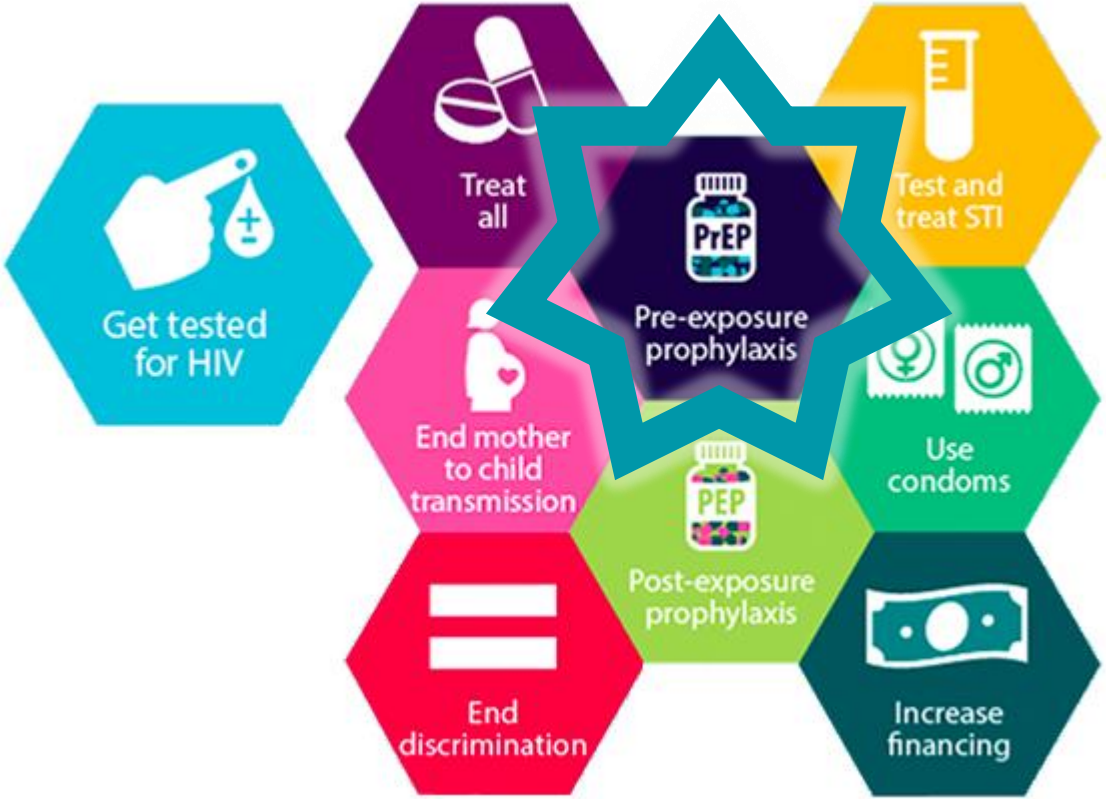
- 23%
New infections/year
relative to 2010

0.7 million
HIV-related deaths

- 39%
Deaths/year
relative to 2010

Source: UNAIDS/WHO estimates

Combination HIV prevention strategies



Overview

- Introduction and Background
- PhD aims and objectives
- Study 1: Systematic Review
- Future Work - Study 2: Qualitative Interviews
- Future Work - Study 3: Survey Design and Analysis

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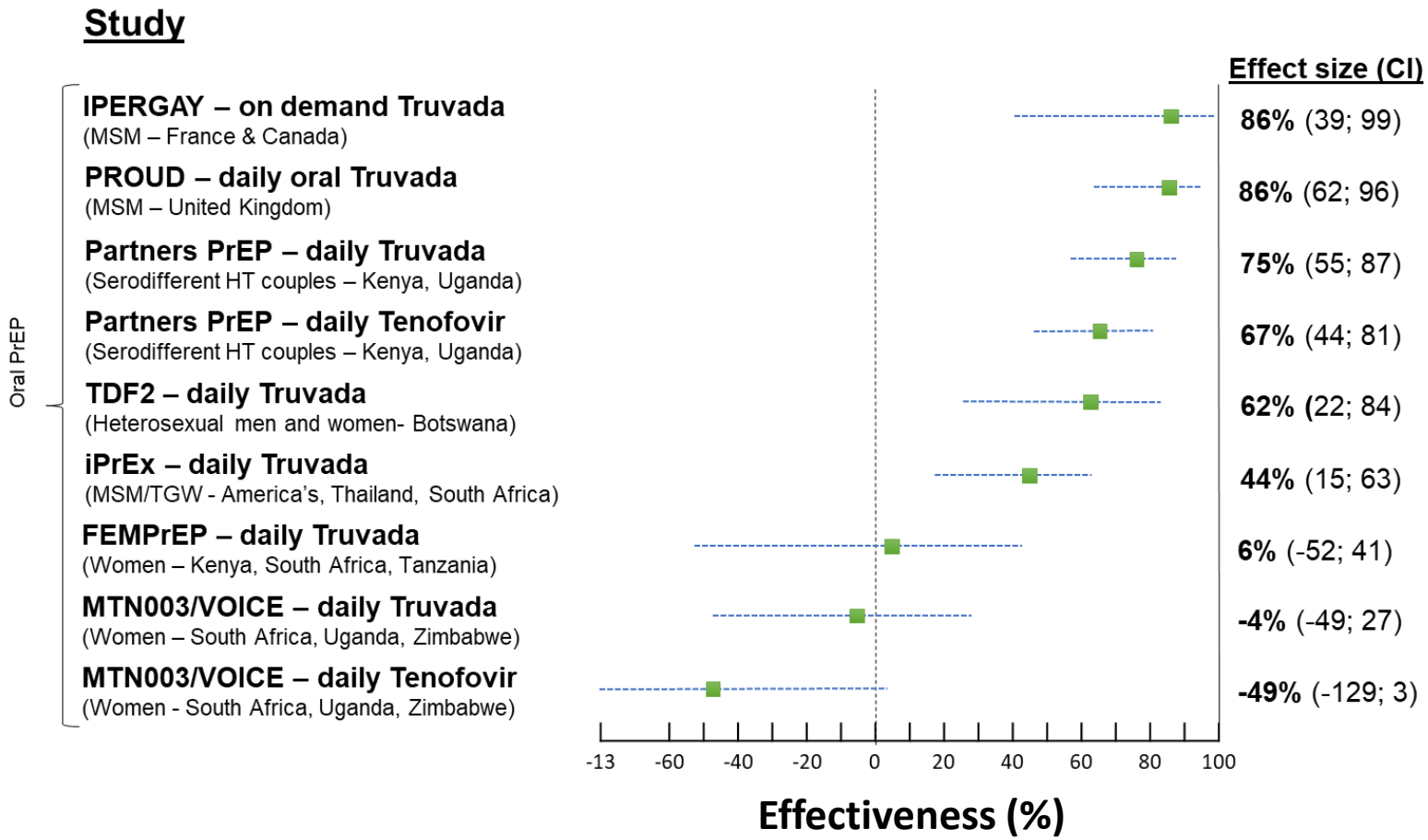
HIV Pre-Exposure Prophylaxis (PrEP)

Biomedical intervention for reducing HIV acquisition

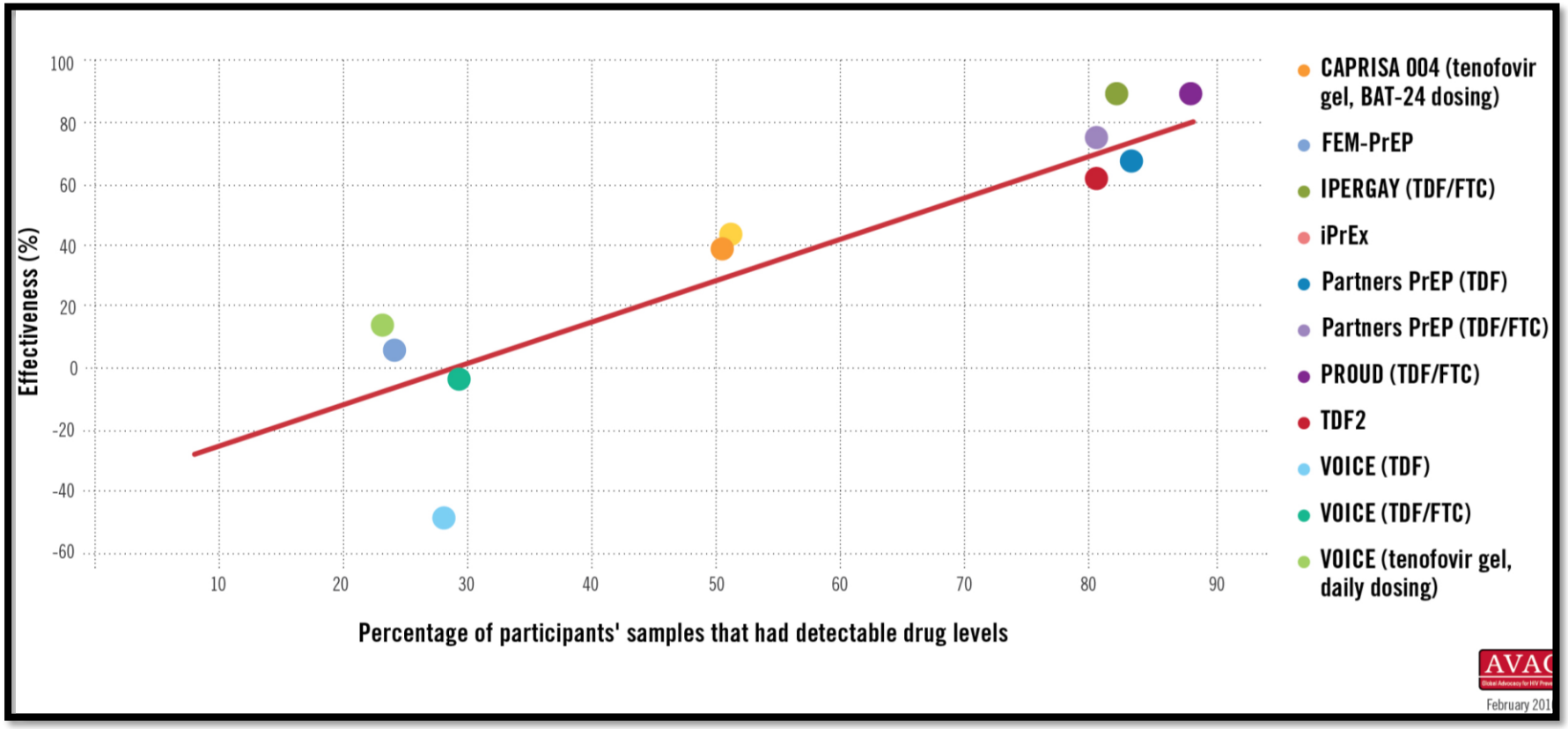
Antiretroviral medication taken **before** exposure

Highly **effective** and **safe**

Evidence for PrEP Efficacy



Differences in efficacy largely explained by adherence



Different forms of PrEP are available

Pipeline: other formulations, implants, long acting injectables

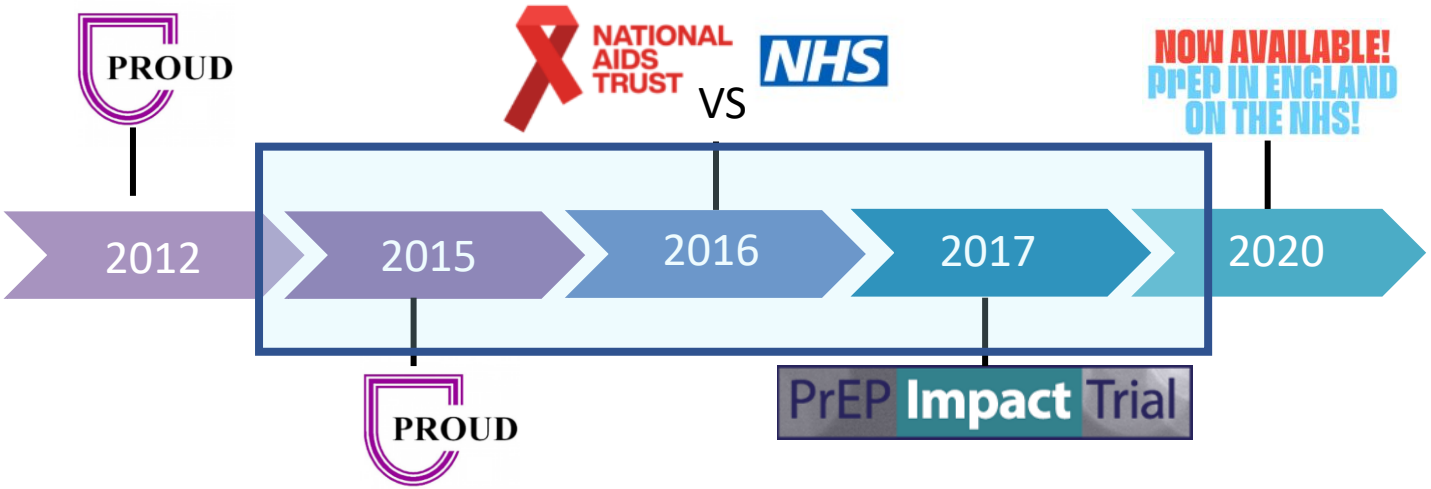
PrEP in England

BASHH
British Association for Sexual Health and HIV

Recommended for people who are HIV negative and at **higher risk of acquiring HIV**

Available from sexual health clinics

PrEP in England

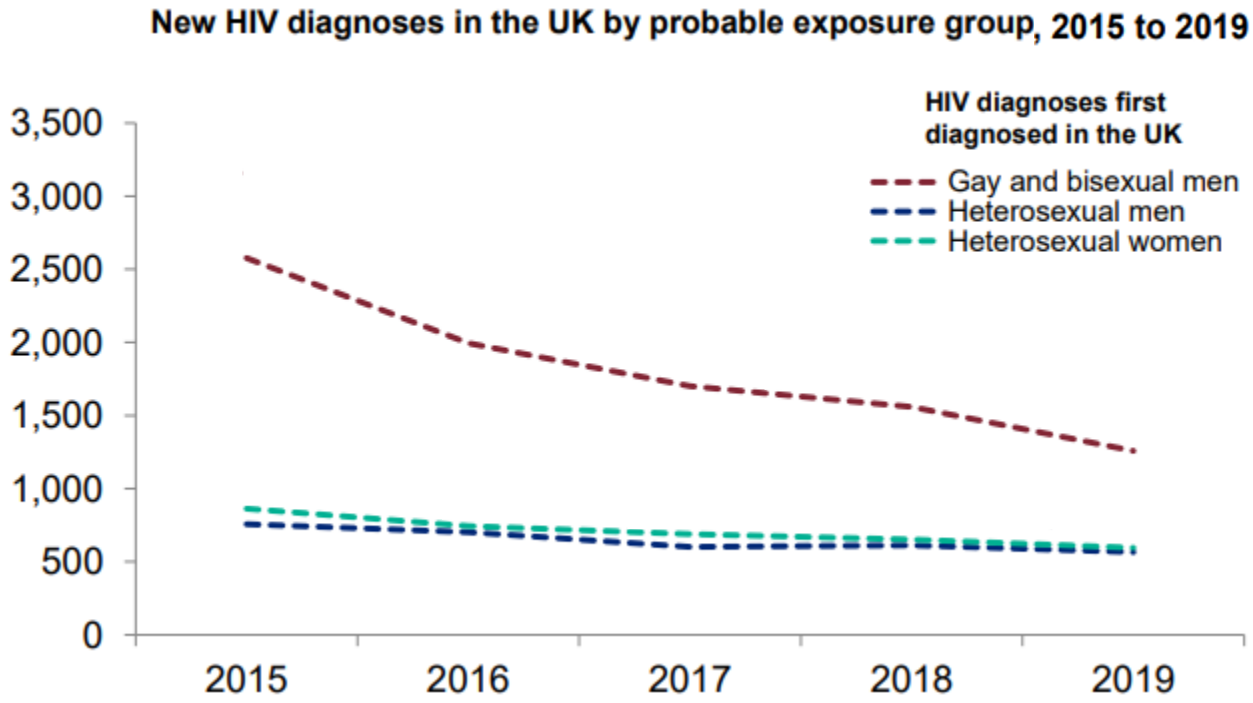


Health Inequity

*Where systematic differences in health are judged to be **avoidable** by reasonable action globally and within society they are, quite simply, unjust. It is this that we label **health inequity**.*

- Closing the gap in a generation: Health equity through action on the social determinants of health (WHO commissioned report on Social Determinants of Health)

Health Inequity and HIV in England



Health Equity Considerations: PROGRESS-Plus

PROGRESS-Plus is an acronym used to identify characteristics that stratify health opportunities and outcomes.

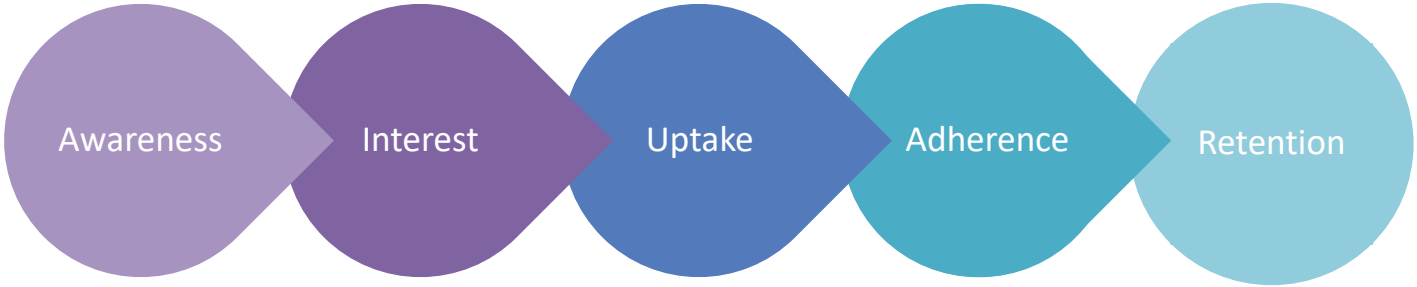
- **P**lace of residence
- **R**ace/culture/ethnicity
- **O**ccupation
- **G**ender/sex
- **R**eligion
- **E**ducation
- **S**ocioeconomic position
- **S**ocial capital

Plus

Additional categories that can attract discrimination, for example:

- Personal characteristics (e.g. age, disability)
- Relationship features (e.g. caring responsibilities)

PrEP Care-Continuum



- **P**lace of residence
- **R**ace/culture/ethnicity
- **O**ccupation
- **G**ender/sex
- **R**eligion
- **E**ducation
- **S**ocioeconomic status
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Plus

Additional categories that can attract discrimination, for example:

- Personal characteristics (e.g. age, disability)
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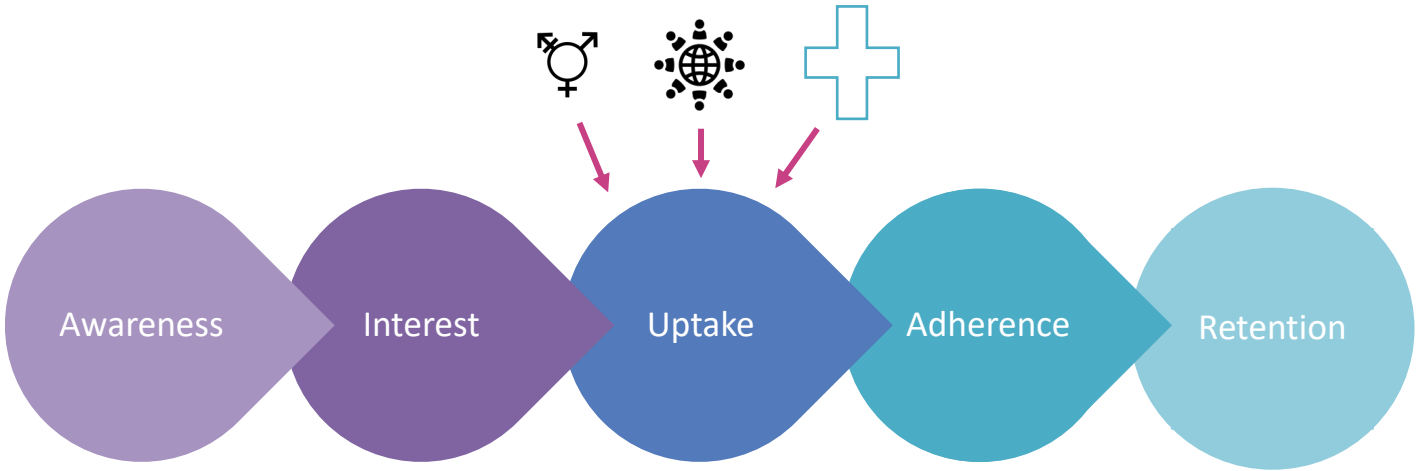
Disparities in PrEP use in England

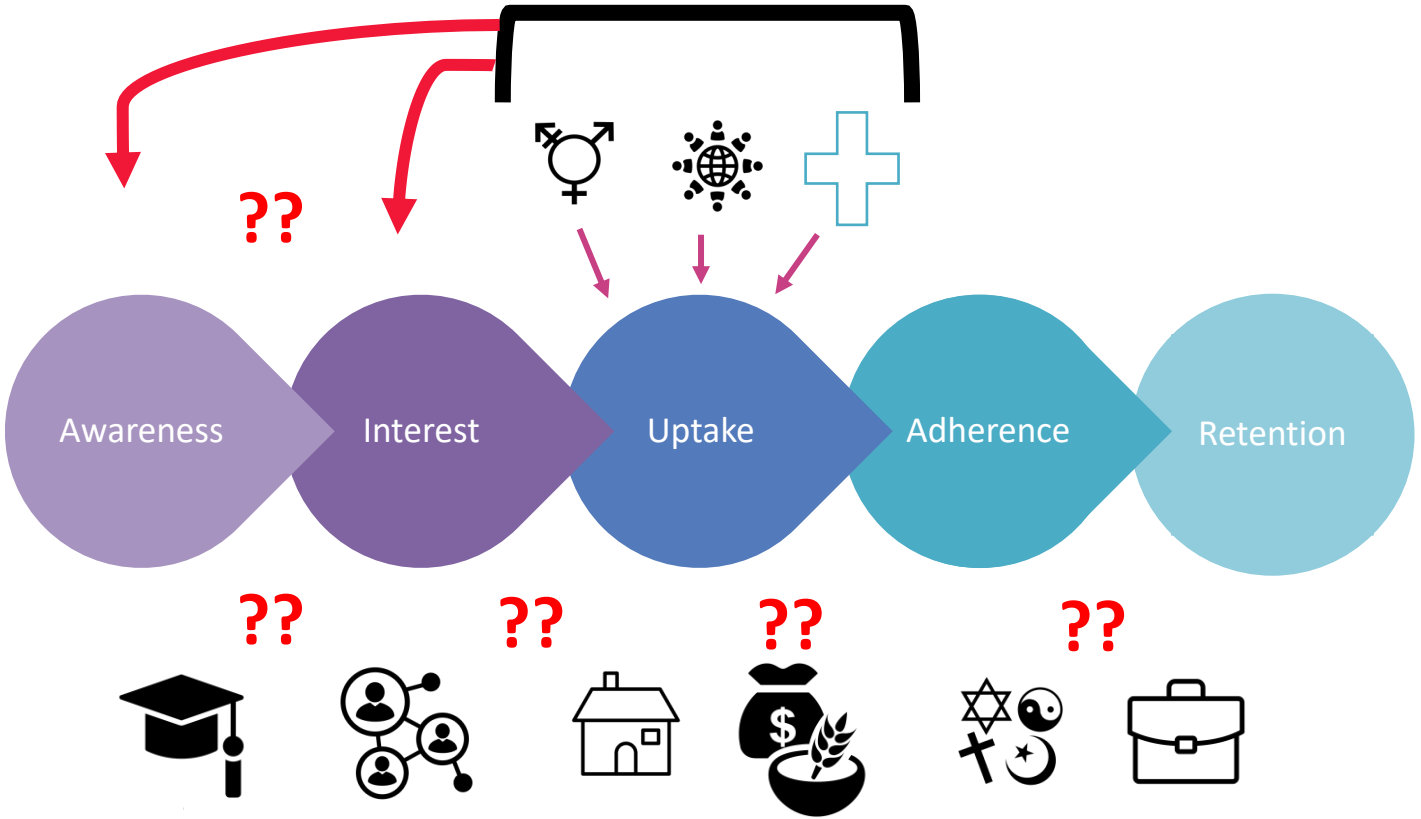


Impact trial: **>95% Men who have sex with men (MSM)**; low use among **younger** MSM

2019 PrEP user survey: **85%** white, low use among **women** and **non-binary people**

385 respondents had tried to access PrEP on the Impact trial but **weren't able to**

Disparities in PrEP use in England



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Introduction and Background

PhD aims and objectives

Study 1: Systematic Review

Future Work - Study 2: Qualitative Interviews

Future Work - Study 3: Survey Design and Analysis

Overall aim

To improve our understanding of how inequities in PrEP provision can be **identified** and **addressed**

PhD Objectives

1. Describe and characterise how outcome measures of the PCC are **defined** and **reported** in real-world settings in high income countries

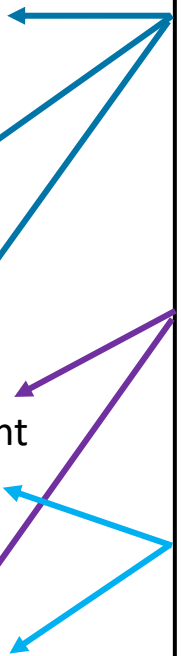
2. Explore how equity parameters are **currently being considered** in evaluations of PrEP provision programmes

3. Investigate which factors that influence health equity are important for **women** regarding the early stages of the PCC (**awareness and interest**)

4. Identify **inequities in PrEP awareness and interest** for women in England

Methodology

1. Describe and characterise outcome measures definitions
2. Explore how equity parameters currently considered
3. Investigate which factors are important for women's awareness and interest
4. Identify inequities in awareness and interest



Study 1: Systematic review of scientific literature published from 2012-2020

Study 2: Qualitative interviews with women in England

Study 3: Cross-sectional survey

Methodology

1. Describe and characterise outcome measures definitions
2. Explore how equity parameters currently considered
3. Investigate which factors are important for women's awareness and interest
4. Identify inequities in awareness and interest

Patient and Public Involvement Panel

AFRICA ADVOCACY FOUNDATION

Sophia

PORN PREP4

NIHR | University College London Hospitals Biomedical Research Centre

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Systematic Review: Aim

Identify and **collate** definitions for outcome measures of the PCC and describe how, and the extent to which, **characteristics that influence health equity are taken into account** in these measures in high income countries

Systematic Review: Objectives

1. Describe how outcome measures of the PCC are **defined** and **reported** in real-word settings in high income countries

2. Explore how PROGRESS-Plus categories are **described** for **study populations**

3. Describe how PROGRESS-Plus categories are **considered** when reporting outcome measures of the PCC

Systematic Review: Methods

HIV/AIDS
Protocol

Equity considerations in outcome measures of the HIV pre-exposure prophylaxis care continuum in high-income countries: a systematic review protocol

Melissa Cabecinha [1], Danielle Solomon [2], Greta Rait [1, 3], John Saunders [3, 4], Hamish Mohammed [5, 6], Lorraine Katherine McDonagh [1, 3]

Correspondence to Melissa Cabecinha; m.cabecinha@ucl.ac.uk

Databases: MEDLINE, EMBASE, PubMed, CINAHL, ASSIA

Search terms based on:

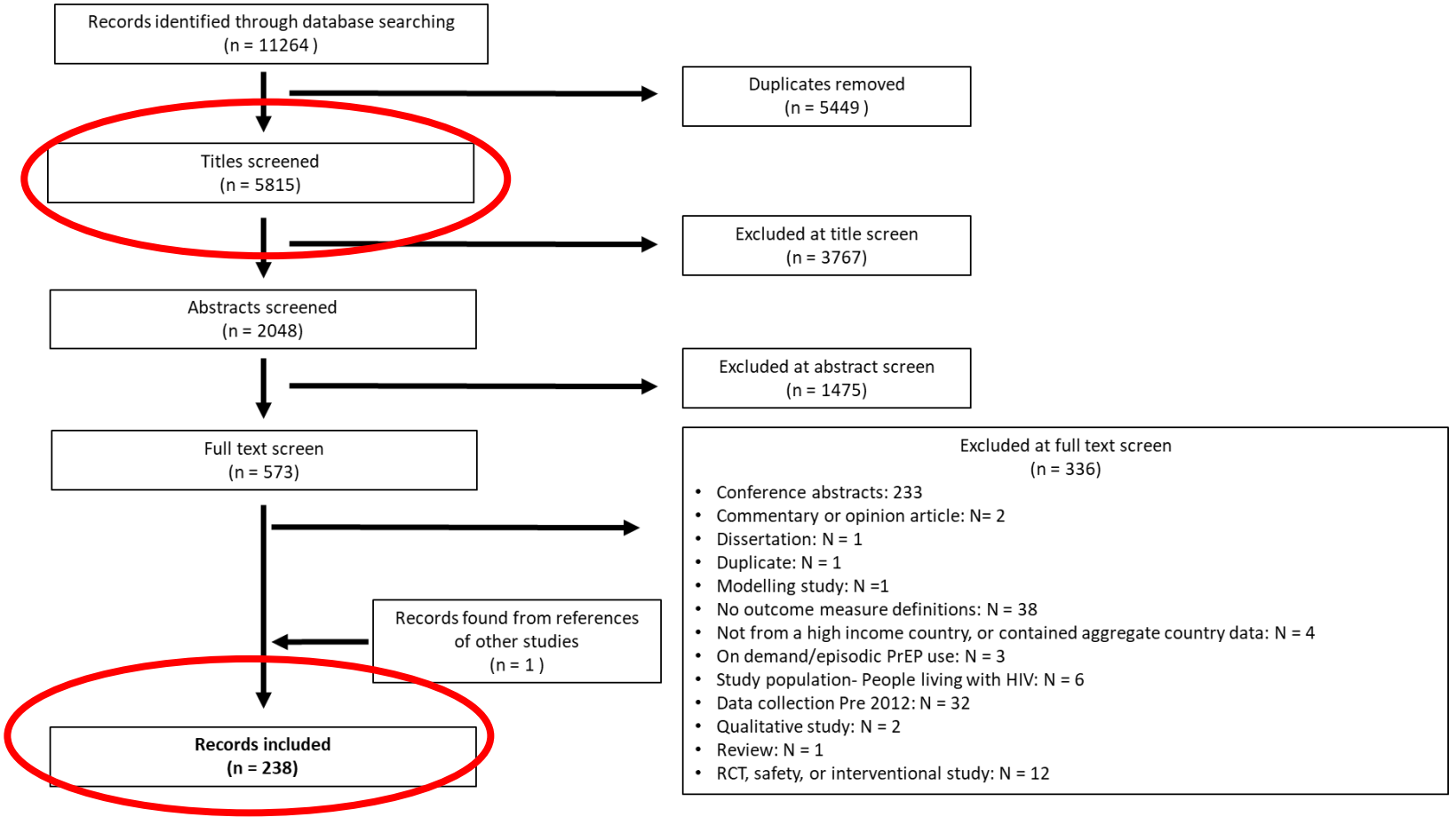
- **PrEP**: e.g. Pre-Exposure Prophylaxis, PrEP, HIV chemoprophylaxis
- **PCC outcome measures**: e.g., awareness, knowledge, interest, acceptability, uptake, use

Limited to articles published between **Jan 2012** and **March 2020**

Systematic Review: inclusion/exclusion

	Inclusion criteria	Exclusion criteria
Population	People resident in high-income countries with a national PrEP provision programme or demonstration/implementation project	People resident in countries without a national PrEP provision program or demonstration/implementation project; people resident in low- or middle-income countries.
Intervention	Studies reporting an outcome measure definition for at least one stage of the PCC in a real-world setting	Studies that do not report an outcome measure definition for the PCC in a real-world setting
Context	Studies conducted in high income countries, as defined by the World Bank country classifications.	Studies conducted in low- or middle- income countries.
Outcomes	Definition for at least one of the following stages of the PCC: awareness, interest, uptake, adherence, retention	Outcomes not in the inclusion criteria
Study Design	Quantitative research studies including non-experimental observational studies	Qualitative studies, review articles, case studies, studies not involving oral emtricitabine/tenofovir disoproxil fumarate as PrEP, randomised controlled trials

Systematic Review: Screening



Systematic Review: Methods

Extraction

Bibliographic information

Study objectives and design

Study populations and demographics

- PROGRESS-Plus categories

Outcome measures

- Definitions
- PROGRESS-Plus categories

Analysis

- Narrative synthesis

Systematic Review: Full text extraction

PROGRESS-Plus Category	Example
Place of Residence	Rural/Urban, country/state/city, housing characteristics
Ethnicity/culture	Ethnic background, country of birth
Occupation	Employment status, employment type (e.g. Professional, skilled, etc)
Gender/sex	Male or Female
Religion	Religious background
Education	Years in/left of education, highest level of education attained, school type
Social capital	Neighbourhood/community/family support
Socio-economic position	Income, means tested benefits, affluence measures

Systematic Review: Full text extraction

PROGRESS-Plus Category	Example
Plus	Age
	Physical or mental/emotional disability
	Sexual orientation
	Other vulnerable groups: Experience of sex work (current or former)
	Other vulnerable groups: Experience of homelessness or unstable housing (current or former)
	Other vulnerable groups: History of incarceration
	Other vulnerable groups: Experience of intimate partner violence
	Other vulnerable groups: Substance users

Systematic Review: Study Characteristics

238 Included studies

Country

78%

12%

3%

Study Design

Cross-sectional	67%
Cohort studies	33%

Population

MSM	49%
Women	8%
Transgender/ Gender diverse	3%
General/other	30%

Systematic Review: Objectives

1. Describe how outcome measures of the PCC are **defined** and **reported** in real-word settings in high income countries

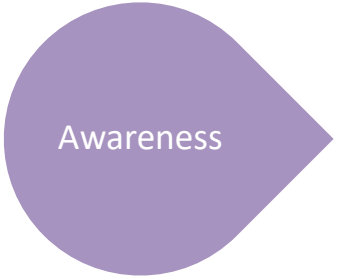
2. Explore how PROGRESS-Plus categories are **described** for **study populations**

3. Describe how PROGRESS-Plus categories are **considered** when reporting outcome measures of the PCC

Objective 1: Results

Outcome Measure	% Reporting outcome measure
Awareness	54%
Interest	50%
Uptake	51%
Adherence	15%
Retention	17%
>1 reported	67%

Objective 1: Results

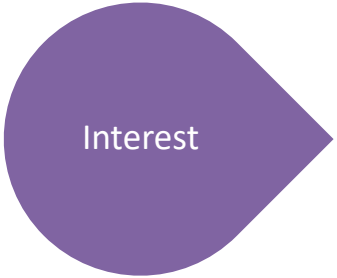


54%, 129/238 papers

"**Have you ever heard of PrEP**?" (Yes/No)

Cross-sectional surveys

No eligibility criteria taken into account



50%, 119/238 papers

"**Interested in PrEP**?" (Yes/No), "**How likely would you be to take PrEP**…?" (Likert scale)

Scenario dependent interest (e.g., cost, efficacy)

Cross-sectional surveys

No eligibility criteria taken into account

Objective 1: Results

51%, 121/238 papers

Use

"**Are you taking/have you ever taken PrEP**?" (Yes/No)

Cross-sectional surveys

No eligibility criteria taken into account

Uptake

Rate of initiation/Number of PrEP prescriptions given

Cohort studies: demonstration projects, health care records

Among population assessed to be **eligible for PrEP**

Objective 1: Results

15%, 35/238 papers

17%, 35/238 papers

"**High**" or "**effective**" adherence

Cross-sectional surveys: **Self report**

Cohort studies: **prescription records**, **biological biomarkers**

Previously validated measures

Retention at x weeks/months, maintaining recommended **appointment schedule**

Discontinuation at x weeks/months:

Gap of x months between visits
Stopping PrEP
Loss to follow up

Cohort studies

Systematic Review: Objectives

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3. Describe how PROGRESS-Plus categories are **considered** when reporting outcome measures of the PCC

Objective 2: Results

PROGRESS-Plus Category	% (N)
Place of Residence	31% (73)
Ethnicity/culture	82% (196)
Occupation	26% (61)
Gender/sex	97% (230)
Religion	0.84% (2)
Education	61% (145)
Social capital	9.2% (22)
Socio-economic position	57% (135)

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Objective 2: Results

PROGRESS-Plus Characteristic	N (%)
Plus- age	89% (213)
Plus- physical or mental/emotional disability or difficulty	8.8% (21)
Plus- sexual orientation	79% (187)
Plus- experience of sex work/transactional sex	6.7% (16)
Plus- history of incarceration	4.2% (10)
Plus- experience of physical/sexual abuse, intimate partner violence	1.7% (4)
Plus- experience of homelessness or housing instability	12% (28)
Plus- substance use	26% (63)

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Objective 2: Results

How are PROGRESS-Plus factors reported?

Income; Area level deprivation; “Do you have enough money to meet your basic needs every month?”

Urban vs Rural; State/County; City

Having a support network; feeling a sense of “community”

Systematic Review: Objectives

1. Describe how outcome measures of the PCC are **defined** and **reported** in real-word settings in high income countries

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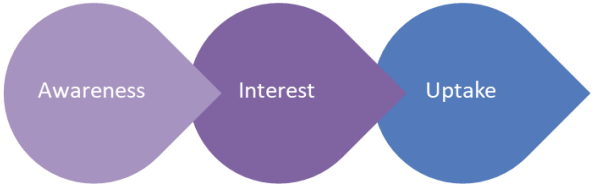
Systematic Review: Summary of Results

Well represented



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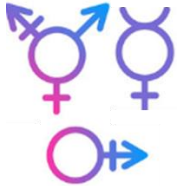
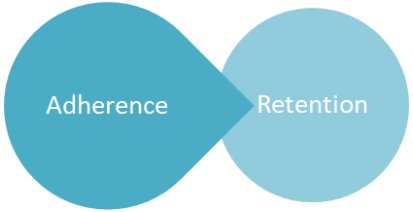
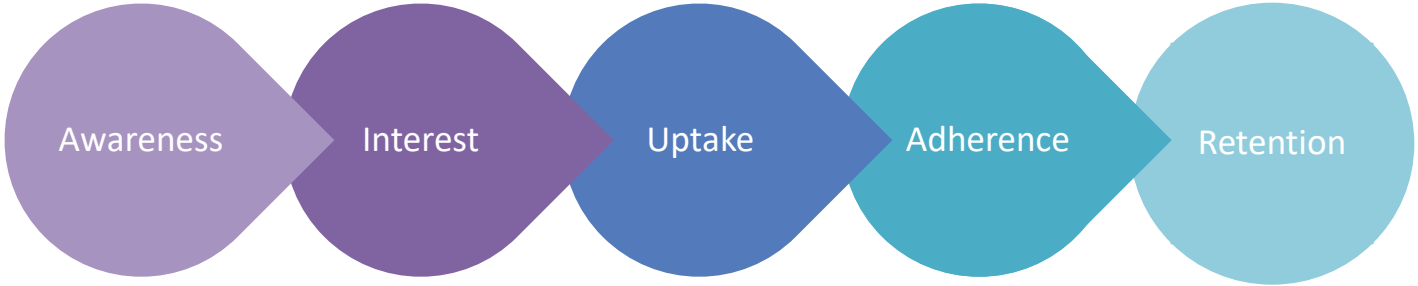




Systematic Review: Discussion



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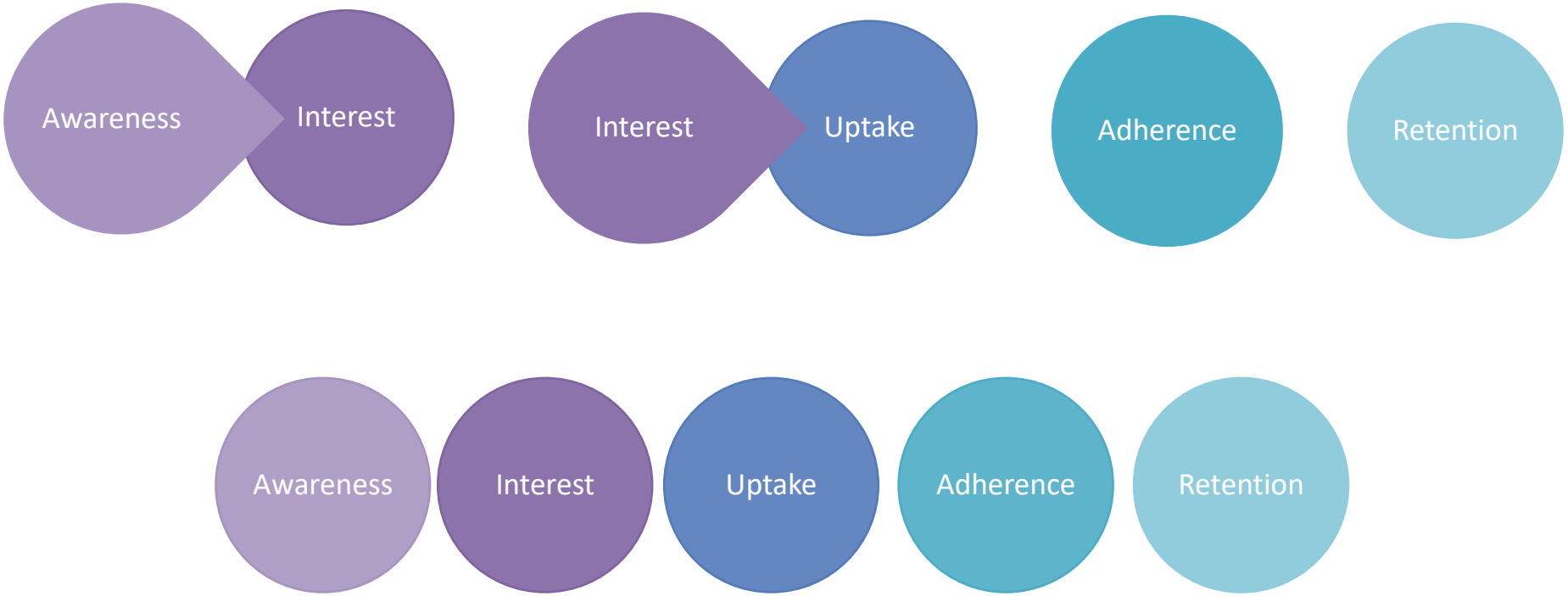


Systematic Review: Strengths

First to collate outcome measures for the PCC in real-world settings

Demonstrates how factors that influence health equity are **described in baseline populations**

Highlighted **gaps** in existing PrEP research

- Populations other than MSM
- PROGRESS-Plus categories

Systematic Review: Limitations

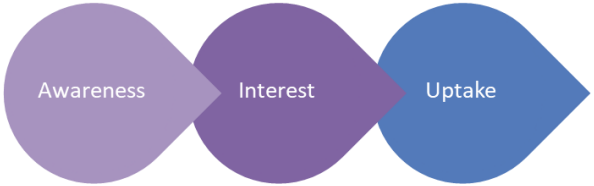
Only **English language** studies included

Only observational- cannot comment on how **equitable** PrEP provision is

Fast moving field!

Systematic Review: Unanswered questions

Well represented



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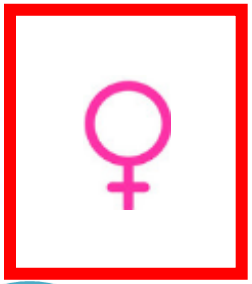
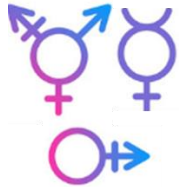
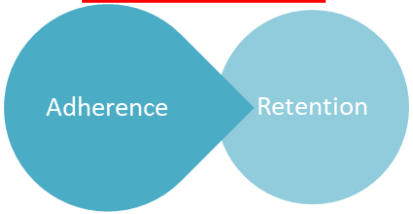
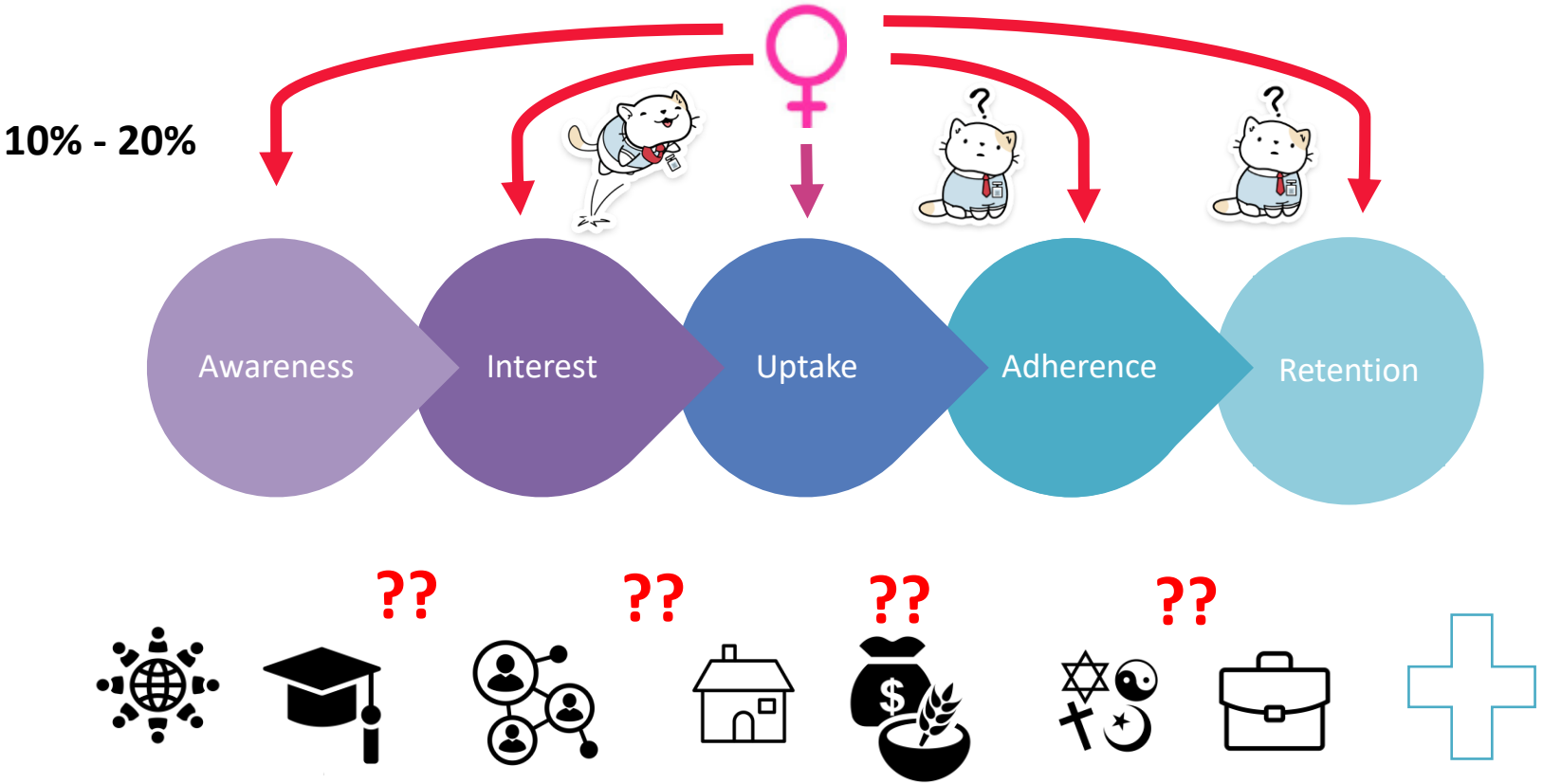






Disparities in PrEP Engagement for Women



PhD – Future work

1. Describe and characterise how outcome measures of the PCC are **defined** and **reported** in real-world settings in high income countries

2. Explore how equity parameters are **currently being considered** in evaluations of PrEP provision programmes

3. Investigate which factors that influence health equity are important for **women** regarding the early stages of the PCC (**awareness and interest**)

4. Identify **inequities in PrEP awareness and interest** for women in England

Overview

Introduction and Background

PhD aims and objectives

Study 1: Systematic Review

Future Work - Study 2: Qualitative Interviews

Future Work - Study 3: Survey Design and Analysis

Project 2 – Aim

Explore **awareness** and **interest** in PrEP among women in England and investigate how **factors that influence health equity** may **impact** women's engagement with HIV prevention and PrEP

Project 2- Objectives

1. Explore women's current **awareness** and **knowledge** of PrEP

2. Investigate whether current PrEP service delivery meets the **prevention needs** and **preferences** for women

3. Discuss how PROGRESS-Plus categories **impact** women's **engagement** with HIV prevention and PrEP

Project 2 – Methodology

Semi-structured interviews 20 – 30 interviews with women in England

What do you know about PrEP?

Who do you talk to about your sexual health?

Does where you live/ your job/ your friends influence decisions about sexual health?

Preferences for accessing HIV prevention?

Is PrEP useful for you or people you know?

Project 2 – Methods

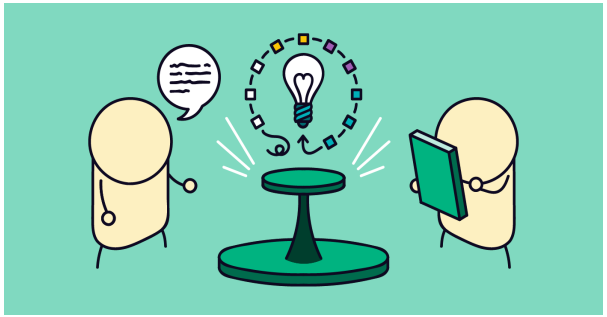
Participants
Women 18+ living in England

Recruitment
Various strategies including: advertisements on social media, HIV prevention outreach sessions, snowball sampling

Purposive sampling

Data collection
Semi-structured interviews via telephone, web conferencing or face-to-face (if permitted)

Topic guides informed by literature review, Study 1 results, and PPI activities



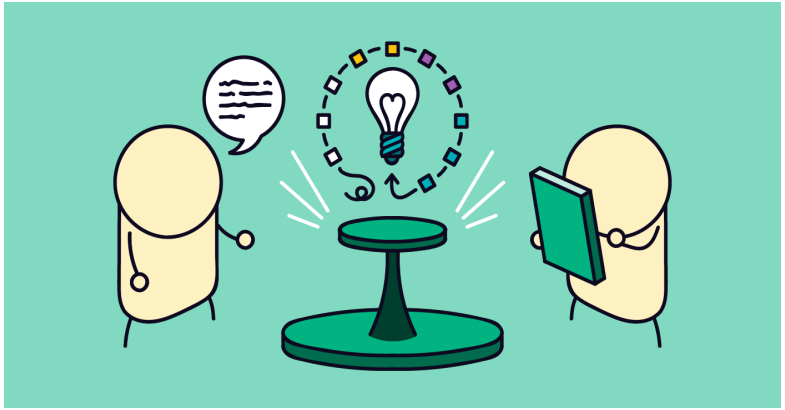
Project 2 – Analysis

Data management
Nvivo software

Thematic Analysis
Familiarisation with transcripts
Coding to identify patterns and generate themes
Themes mapped to existing models/frameworks if appropriate

Results
To inform design of **Study 3**

Project 2 – Progress



Ethics forms on track for submission (**June 4th**)

Draft materials (**advertisements**, **topic guides** etc.) underway

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Project 3 – Aim

Examine women in England's **awareness and interest** in PrEP and **identify inequities** in PrEP awareness for women

Project 3 – Objectives

1. Assess women in England's **awareness of**, and **interest in**, PrEP

2. Identify and quantify **relationships** between **factors influencing health equity** and women's awareness of **PrEP**

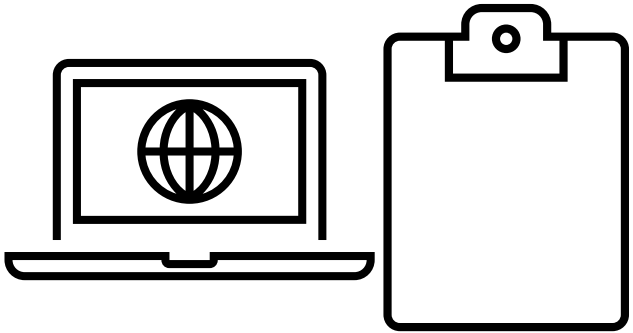
3. Investigate women's **preferences** for PrEP service delivery in England

Project 3 – Methods

Design
Cross-sectional, self-completed online survey

Participants
Women 18+ living in England

Recruitment
Similar methods to Study 2



Data Collection
Online questionnaire using UCL's Research Electronic Data Capture (REDCap) software
Questionnaire informed by literature review, results of Study 1 and Study 2, and PPI activities

Project 3 – Analysis

Data Management

R and R studio

Analysis

Descriptive statistics for demographics, PrEP interest and awareness

Regression analysis to evaluate the relationship between PrEP awareness and key equity factors

Project support and design

Survey design and analysis course (June 2021)

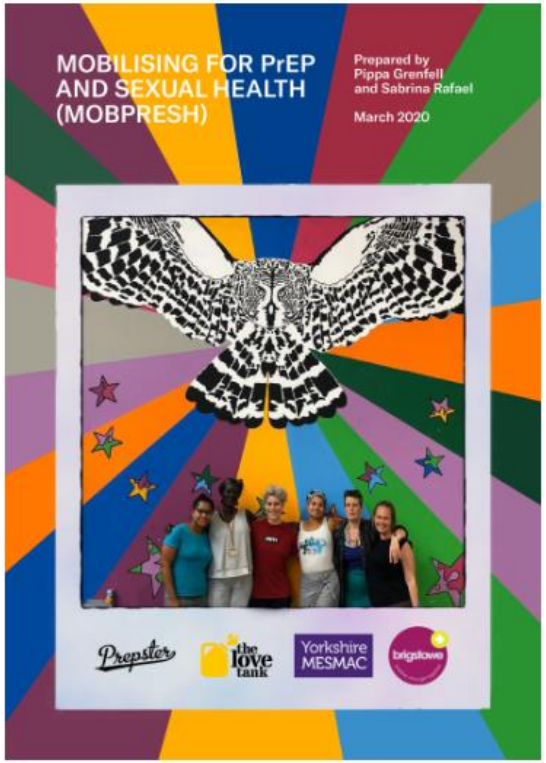
Study Impacts

1. Identify equity factors that **important for women** in regards to PrEP

2. Provide a **benchmark** for PrEP awareness and interest for women in England

3. Inform **interventions/campaigns** to increase PrEP awareness

Some great work is already being done



https://prepster.info/

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Many Thanks

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Grant code: MR/N013867/1