Full title of Project

The REACH study: Exploring patterns of Retention and Engagement Across specialised Care services of HIV positive patients in the United Kingdom (UK)

Aims and objectives

The REACH study aims to explore, describe, and understand HIV out-patient attendance (OPA) in people living with HIV (PLWH), in order to develop cost effective interventions to optimise their engagement in care.

Objectives:
1. To examine HIV OPA patterns amongst PLWH.
2. To identify predictive factors of disengagement.
3. To calculate the health and financial costs of disengaging from care.
4. To develop a retention-risk assessment tool.
5. To understand the situational, environmental, behavioural and social factors which influence OPA.
6. To develop intervention models to improve engagement in care, to be tested in future studies.

Background

The introduction of combination anti-retroviral therapy (cART) has led to a dramatic reduction in HIV-associated morbidity and mortality.[1] More recently cART has also been recognized as an effective means of reducing HIV transmission.[2] Yet this individual and public health benefit can only be achieved if PLWH are aware of their infection and have sustained engagement with HIV care. In 2010 over 100,000 adults were estimated to be living with HIV in the UK.[3] Approximately one quarter were unaware of their infection but of those that were aware almost 20% were 'lost to follow up'.[3]

In response to direct observations that poor engagement, poor outpatient attendance (OPA) and resultant loss-to-follow-up (LTFU) are associated with increased odds of mortality and poorer virological suppression,[4,5] the past decade has seen increasing focus on this important area. To date most studies have been limited to measuring the frequency of lost-to-follow-up, usually defined as someone not seen for care within a 12 month period, and identifying the associated demographic characteristics.[6,7] Complex patient groups, such as intravenous drug users, migrants and the newly diagnosed are more often lost-to-follow-up.8 Analyses of those lost to follow up have revealed that approximately 28% return to care within a median of 3.5 years.[9] Patients with a period of LTFU in their clinical history had poorer health outcomes.

Missed out-patient appointments also have significant resource implications for National Health Service (NHS) service providers. The financial cost of missed appointments in the NHS has been estimated at £360 million per year.[10]

Recent analysis of the national Survey of Prevalent HIV Infections Diagnosed (SOPHID) dataset between 1998 and 2007, found nearly 5% of patients were lost to follow-up in any one-year, a further 4% being intermittent attendees.[11] In total 19% of adults seen for HIV care in this period were lost-to-follow-up by the end of 2007. Similar findings were found in an analysis of the UK Collaborative HIV Cohort (UK CHIC) with 17.4% of patients potentially lost to follow up.[12] Two distinct patient subpopulations have emerged from research to date: those permanently lost-to-follow-up and those temporarily lost (i.e. those who re-present at the same or different centre).

Researchers have assessed retention and LTFU in a number of different ways.[6-9,13] Many utilise attendance data (visit times) over an arbitrarily defined time period, typically one year. One inherent limitation in this approach is that patients may be infrequent attenders despite regular scheduled appointments, rather than non-attenders, and that the frequency of clinical visits will be based on clinical need. A surrogate marker must distinguish between these populations. CD4 count measurements have been used as a surrogate marker of attendance,[12] however this approach may become difficult as guidelines for patient monitoring are revised. Most clinics do not formally collect data on LTFU. Therefore the identification of predictive factors and markers of OPA and LTFU in this study becomes crucial. Our study will also provide a significant knowledge base to inform estimate calculations of LTFU adjustments needed for UK HIV cohort analyses. Findings may also be directly applicable to other chronic diseases.

These data provide the impetus to expand the evidence base in this area. The literature to date does not adequately characterise the differing patterns of OPA and health seeking behaviour amongst PLWH, and has largely explored only demographic correlates. The phrase 'engagement in HIV care' comprises the distinct but interrelated processes of linkage to care after HIV diagnosis and retention to care. It may be conceptualised as a continuum from PLWH unaware they are infected, to PLWH who are fully engaged in specialised care. PLWH who are aware of their HIV status and not receiving any care, those who entered care but who subsequently disengage and infrequent attenders all fall at various positions on the spectrum. Throughout the course of their disease, PLWH may move across this care continuum.

The goal of a better understanding and a means to predict disengagement is essential for both individual and public health benefit. This study is a crucial step in moving NHS HIV services forward from a recognition of this phenomenon to developing innovative strategies to maintain patient retention. It has the potential to be of substantial benefit in terms of resource-allocation and patient outcomes.

Need

Retention in HIV care is vital for treatment success at both individual and population levels. Good engagement is associated with improved adherence, virological and immunological outcomes and survival.[14] Despite ongoing efforts by clinical services, delayed linkage and poor retention in outpatient HIV care represents one of the major challenges of optimising patient outcomes.

The proposed study is particularly timely in this current context of expanded HIV testing and the development of treatment as a form of secondary HIV prevention.[14] Whilst earlier diagnosis is the first step, improvement of clinical and public health outcomes relies on continued engagement with services. Innovative models of care targeting early HIV identification must complement strategies promoting long-term integration into care. Without these, poor retention may ultimately limit the predicted beneficial impact of wider testing and treatment on the future spread of the HIV epidemic in the UK.

The proposed study will systematically define the complex patterns of HIV OPA in the UK, calculate the health and financial costs of disengaging or partially disengaging from recommended OPA schedules and undertake exploratory work to inform the design of future interventions to meet the diverse needs of PLWH. This study will respond to the health needs of this NHS user group. It will provide invaluable insight, identifying barriers to, and preferences for, service utilisation. It will allow NHS clinics to tailor resources that promote regular service engagement, particularly among those found to be at increased risk of disengaging from care.

Methods

The three year collaborative study will bring together major HIV treatment centres and key HIV community stakeholders across the UK, drawing additional insight from international research partners.

We will undertake the research in three phases.

Phase 1: Detailed analysis of the UK CHIC database and predictive modelling

Phase 1 will examine and define HIV OPA patterns (Objective 1), identify predictive factors of disengagement (Objective 2), enable calculation of the health and financial cost of disengagement (Objective 3) and contribute to the development of a retention-risk assessment tool (objective 4)

The first phase of the proposed study will comprise of secondary analysis of the UK Collaborative HIV Cohort (UK CHIC) database to examine the patterns of HIV care attendance and to identify related demographics. Criteria of attendance and retention to care will be identified.

Description of UK CHIC: UK CHIC collates data relating to the clinical care and treatment of PLWH across 15 UK HIV services. This database contains more than 45,000 records of patients since 1996 and has been shown to be broadly representative of persons living with HIV in the UK. The current data set provides data on basic demographics, AIDS diagnoses, antiretroviral treatment, CD4 counts, and viral loads on HIV positive individuals aged over 16 years who have attended one of the collaborating centres for care, patients are followed for as long as they are in care. It provides a unique opportunity for a sophisticated analysis of attendance patterns.

Until recently, the database did not capture clinic visits from all participating clinics thus CD4 counts and viral loads have traditionally been used as surrogates of attendance. This will continue to be the case, although information on out-patient attendances are now available for a subset of participating clinics. Where available this data will also be used, and will help validate surrogate markers.

The UK CHIC records will also be linked with national surveillance data including the Survey of Prevalent HIV Infections Diagnosed (SOPHID), and with mortality data from the Office of National Statistics for England and Wales, and the General Registrar Office for Scotland. This linkage will help to reduce bias related to possible confounding by duplication of entries, patient transfer between centres and mortality

Preliminary unpublished analysis of UK CHIC[15] suggests there are subpopulations within those potentially disengaged with differing patterns of attendance, characteristics and outcomes. Further detailed analysis of these populations will be performed in the proposed study.

Data analysis: Group-based trajectory modelling is an increasingly used, specialised application of modeling.[16] It is designed to identify clusters of individuals following similar, distinctive progressions of some behaviour or outcome over age or time. Logistic regression analyses can then be used to predict the probability of an individual being within a particular group according to a particular set of risk factors. Use of this strategy would provide a unique, statistical snapshot of the key characteristics and behaviours of this complex population. We plan to apply these methods to the UK CHIC dataset to identify distinct broad groupings of individuals according to their pattern of engagement to services. Modelling techniques will be applied to the data to refine these clusters and trace group-specific outcomes. The data will try to establish whether OPA patterns vary regionally across the UK and highlight whether future explorative work is needed beyond London clinics (see Phase 2).

International collaborators: Researchers at the Basel Institute for Clinical Epidemiology & Biostatistics have utilised a similar technique to explore and describe patient adherence to anti-retrovirals in the Swiss cohort study.[17] Their input will be sought in our design and analysis process.

There are noted centres within North America, which have similar profiles of epidemic and retention. Comparative analyses of their cohort data will also be performed to identify patterns and experiences which may be translated into effective outcomes in the UK NHS setting.

We will measure the costs associated with disengagement in terms of its impact on health and HIV management costs. We will investigate the potential health impact of disengaging with care in terms of mortality, and disease progression. Our approach will be to regress these outcomes against exposures defined in terms of levels of engagement, controlling for mediating factors, such as CD4 counts and clinical stage at diagnosis. This will provide estimates of the impact of disengagement on the incidence of and timing to more severe HIV disease states. However, the interpretation of any results will be limited for several reasons: (i) reverse causality (return appointments are likely to be scheduled less frequently in individuals who are well); (ii) lack of power for the most important clinical endpoints (most AIDS events and deaths now occur in newly diagnosed patients, thus differential attendance patterns are unlikely to have a strong impact on these specific outcomes in this group); (iii) the lack of resource utilization data captured in UK CHIC.

The main approach to the analysis of the impact will be via the use of mathematical models. We will utilize HIV Synthesis, an existing model for HIV disease progression developed by Prof Andrew Phillips at UCL, which simulates the full course of an individual's HIV infection.[18-20] We will modify this basic model structure to introduce differential patterns of attendance (based on data obtained from Phase I) and to assess the impact of these on virological failure, resistance development, CD4 responses to therapy and subsequent clinical progression. We will then apply utility scores and NHS costs to clearly defined health states within the model, based on published UK estimates and NHS reference costs – this will allow us to model disease progression, quality-adjusted life years and NHS costs, at different levels of engagement, and will also allow us to calculate the cost of the clinic appointments missed by partial engagers and disengagers. This will provide one component of the cost to the NHS of disengagement with care. These data will be derived within Phase 2 and be determined through patient records and electronic/clinical databases Key outcomes: HIV care attendance patterns, criteria for defining subpopulations of care engagement, proportion of patients who disengage from care, typical length of disengagement, proportion of patients that re-engage with care, factors associated with delayed linkage and poor retention to care, health impact of partial or non-engagement and associated financial cost.

Key outputs: Findings will guide the development of a "retention risk" assessment tool. Independently this may be used by HIV care services to identify those at risk. This tool will be applied to a sample of patients to be followed over a 12 month period to determine if it is predictive of the identified patterns of attendance.

Phase 2: Examining patient experience

The second phase of this study comprises of quantitative and qualitative methods to understand the situational, environmental, behavioural and social factors which influence OPA (objective 5). Findings will inform development of intervention models to improve engagement in care (objective 6).

A quantitative survey followed by a nested qualitative sub-study will be conducted across five London HIV treatment centres providing outpatient HIV care. The varied patient cohort sizes, composition, and models of service delivery, provided by these clinics helps ensure the study's findings will resonate with clinics throughout the UK. Each of the collaborating study centres will be required to nominate a key worker to facilitate recruitment and engagement with the study.

Inclusion criteria: According to criteria identified during phase one of the study, the nominated key worker will identify HIV patients within each pattern of engagement subgroup over a six month period. These patterns of attendance may include: Patients established in continuous regular care; Patients with intermittent attendance; Patients lost to follow up for longer than one year; and Patients re-established following a period of disengagement.

Phase 2a: Quantitative Component - Survey Questionnaire

Patient identification and recruitment: In-hospital databases and electronic records will categorise patients according to OPA patterns. Within each category a random selection of patients will be identified to approach by the key worker when they next attend or by phone and or letter if not currently fully engaged with care and contact details available.

Patients lost to follow up for longer than 1 year will be actively traced by phone, text, letter or via their GP. In terms of telephone contact, a maximum of five telephone calls will be made to contact clients, each call at a different time and day. Only staff involved in the patient's clinical care will make initial contact with the patient and referral to the study team will only occur with the patients consent. If these conventional methods fail, assertive outreach via the UK Community Advisory Board (UK-CAB), peer-to-peer networks and community nurse specialists will be explored if ethical approval obtained. Patients' re-established in care following a period of disengagement will also act as a surrogate population for those currently disengaged.

At recruitment, patients will receive information summarising the study and its key objectives. Informed consent will be required. Once recruited, a convenient time and location for completion of the study components will be confirmed.

Study instruments: An anonymised confidential self-completion questionnaire will be used to obtain quantitative data related to patients' health beliefs and utilisation of HIV services and the behavioural and access-related factors associated with their pattern of engagement. The explanatory variables will follow the framework provided by the behaviour change wheel model,[21] which has three essential conditions: capability, opportunity, and motivation at its centre. Within this we will specifically explore treatment beliefs, and in particular necessity beliefs and concerns[22], and see how these link with patient attendance patterns. Whenever possible, the questionnaire will incorporate validated items used in other large-scale behavioural surveys.

The questionnaire will be available in English and up to two other languages. Languages will be determined following outcomes from the UK CHIC analysis. The survey will be available in paper format and electronically (online). For those patients currently disengaged from HIV services and unwilling to re-attend, the survey will be available via an online link including formats suitable for smart phones. The software package, SNAP, will be used. Patient privacy and confidentiality will be central to survey and study.

Sample size: A sample size of 250 'disengaged' patients and 250 'partially disengaged' patients with a comparison group of 500 engaged patients will be recruited. Assuming a 70% response rate to the questionnaire in the engaged group and at least 50% in the disengaged groups, we will require 500, 500, and 715 eligible patients to be invited to participate in the three patient groups respectively. These sample sizes are achievable given the total cohort size of at least 10000 patients under care, and assuming that each of the two disengaged groups has a prevalence of least 5% in the cohort. These sample sizes will provide over 80% power when either disengaged group is compared with the control group to detect a difference in the prevalence of a suspected predictor of disengagement when the population difference is 56 vs. 44% or 14 vs. 7%, at a 5% significance level.

Piloting: A pilot will be undertaken before full-scale recruitment to ensure the feasibility and acceptability of the questionnaire to patients. The pilot will explore patients' understanding of the key terms and constructs included in the questionnaire. The pilot will involve i) recruitment of five respondents ii) monitored self-administration of the questionnaire to explore the understanding of key words and constructs, timing, questions asked by respondent and iii) review of questionnaire.

Data collection and analysis: Descriptive analyses to present summary statistics for each of the three engagement groups (disengaged, partially disengaged, control) and the use of standard univariate statistical tests to compare these three groups. Multivariate logistic regression analyses will be used to identify and assess independent associations with engagement.

We will apply unit cost data from NHS reference costs and standard published sources to calculate the cost of the clinic appointments missed by partial engagers and disengagers. This will provide one component of the cost to the NHS of disengagement with care.

Key outcomes: HIV care attendance patterns, factors associated with delayed linkage and or poor retention to care, financial cost of partial or non-engagement.

Phase 2b: Qualitative Component - In-depth Interviews

A qualitative sub-study will use semi-structured in-depth interviews to develop a contextual understanding of the factors that influence continued engagement with care.

Patient identification and recruitment: On completion of the quantitative questionnaire (Phase 2a) patients will be asked if they would be willing to participate in the in-depth interviews, and if so to provide contact details (email or phone number). A member of the research team will subsequently contact the patient to assess eligibility according to a quota system and arrange an interview at a mutually convenient time and location. Interviewees will be offered £20 at the end of the interview in recognition of the time involved. Interviews will be conducted face to face when possible however phone interviews and the use of online chat will also be available.

Study instrument: All interviews will be based on a topic guide which will cover key areas for investigation such as the patient's own experience of health care organisations, personal influences and motivation of health seeking behaviour. The interviews will be conducted with assistance of Language Line interpreting services when needed. It is estimated that the interviews will last up to two hours.

Sample size: A purposively selected sample of approximately 40 eligible respondents will be recruited over a 6-month period. The sample will be designed in order to ensure maximum diversity in terms of key socio-demographic and clinical variables. For a sample of this kind, where a heterogeneous community is being studied, the quota criteria for selection will likely include gender, age, ethnicity, transmission risk group and stage of disease in conjunction with pattern of OPA.

Piloting**:** Taking a similar format to the piloting of the questionnaire, a pilot will be undertaken to explore patients' understanding of the key terms and constructs included in the topic guide for the interview.

Data collection and analysis (for all qualitative components including phase 3): Interviews and focus groups will be recorded and transcribed verbatim. The recordings and transcripts will be kept in a locked area separate from any identifying data. Analysis will be based on grounded theory, which is focussed on localised accounts and experiences of the sample population.[23] Thematic and comparative analysis of interviews will be performed using ethnographic software, NVivo. This programme enables synthesis of verbatim data within a thematic matrix elucidating conceptual associations.

Key outcomes: The outcomes of this phase will be used to propose service delivery models tailored to the different sub-populations.

Phase 2c: Community Focus Groups

Supplementing the in-depth interviews will be community focus groups facilitated by our UK CAB representative. Up to four focus groups will occur with a maximum of 15 participants. The groups will be conducted by an experienced qualitative researcher supported by a note taker. With the permission of participants, the sessions will be recorded and transcribed verbatim. The four groups are likely to comprise of women only, gay men, an African/migrant group, and a service user group.

These focus groups will be used to uncover alternative perceptions that may be articulated in a different, non-medicalised setting. It may also serve to access those patients who fail to engage to medical services but continue to engage with their extended community network. The stated purpose for the focus group will be to explore patients' experiences, their service preferences and perceived barriers to accessing HV services.

Phase 3: Key Informant Study

The final phase of this study also aims to understand the situational and environmental factors which influence OPA (objective 5) to inform development of intervention models to improve engagement in care (objective 6), however it explores the service providers perspective.

25 semi-structured interviews with service providers and funders will be used to explore ways to optimize patient engagement. A sampling frame defined according to key constituencies in the field of HIV service provision will be created. Our sampling frame will include organisations from within each of six identified constituencies: clinical services; public health; academia; voluntary sector; health promotion; and policy. Within each of these constituencies it is possible to identify key organisations and subsequently key informants from within these organisations.

All prospective informants will be approached by email or phone, and if agreeable a face to face interview arranged.

A topic guide will be used to explore ways to optimise engagement and potential impact on service delivery and costs. We will undertake preliminary analyses to calculate the costs of the proposed interventions from a societal perspective. These will include the costs to organisations from providing the activities to increase engagement and the costs borne by participants in attending them. We will also investigate potential for cost savings in terms of the impact on use of NHS services.

Key outcomes: list of potential interventions to improve and optimize engagement; preliminary estimates of the costs of these interventions.

Contribution to collective research effort and research utilisation

The potential benefit of this research aligns with the wider NHS' priorities of driving and achieving quality and efficiency within service delivery. It is important to develop a service which is flexible and responsive to the needs of the service users. The outcomes of this research represent a fundamental part of tailoring national HIV services to improve patient-centred care and health outcomes.

A retention risk tool will be devised and this study will represent the first part of its future validation process. The tool will ultimately be a practical algorithm that could be incorporated into clinical practice of multi-disciplinary caregivers of HIV patients. The qualitative outcomes will directly inform innovative service strategies, streamlining and building on current initiatives to engage HIV patients. Identified key factors will provide a theoretical framework to develop behaviour change interventions. Detailing the economic impact of such alternative models will be crucial to promote its uptake in care services.

Maintaining patients in HIV care is pivotal if there is to be any population benefit of HIV treatment on the prevention of transmission. In this way this study will lead to knowledge that ultimately have direct impact on national public health practice.

The project team aims to enable practitioners and policy makers to apply our findings and guidance in a robust and timely manner. Our dissemination strategy has been developed to support this process. The strategy will leverage existing resources within the participating organisations, such as their academic infrastructure, professional relationships and community networks fully. We will work closely with UCL's well-established Public Engagement Unit. The UK-CAB will be integral to dissemination.

Four key platforms are proposed:

- **Peer reviewed publications**: we will publish in high impact peer reviewed journals and work with UCL's Public engagement unit to broaden the audience to include service users and practitioners as well as academic researchers.
- **Conferences and seminars**: findings will be disseminated at local, national and international conferences and seminars. We will also present at smaller and more interactive forums aimed at community based organisations and service users.

- **Newsletters and briefings**: distribution of a regular newsletter summarising study findings will be used to update participating centres. Paper-based and web-based literature will be also be disseminated to community agencies and national HIV primary, secondary and tertiary care providers.
- **Feedback meetings**: we will present at each participating centre to outline the outcomes and highlight their centre's contribution

Approval by Ethics Committees

This study aims to explore the differing patterns of outpatient attendance and health seeking behaviour amongst PLWH. It will require participants to discuss issues of a personal and sensitive nature. This may prove distressing to some individuals. Specialist health care professionals – psychologists, health advisors, nurses and doctors – will be available to provide any necessary support. Input and guidance from the proposed advisory group will ensure that research tools are appropriate and acceptable.

The proposal will initially be reviewed by the UK CHIC steering committee. Agreement to collaborate has been granted from the proposed HIV service sites. The questionnaire, topic guides and protocol will be submitted to the integrated research applications system (IRAS) and appropriate research and development office for approval.

Plan of investigation and timetable

	2012		2013				2014				2015	
	3	4	1	2	3	4	1	2	3	4	1	2
Create advisory committee	🟦		x		x		x		x		x	
Phase 1: Detailed analysis of UK CHIC												
Analysis of outpatient attendances	🟪	🟪	🟪	🟪								
Validation with SOPHID and ONS	🟪	🟪	🟪	🟪								
Health impact analysis of non-attendance			🟪	🟪	🟪	🟪						
Predictive modelling & algorithm development			🟪	🟪								
Evaluation of predictive algorithm					🟪	🟪	🟪	🟪				
Phase 2: Examining patient experience												
Quantitative Research												
Ethics approval	🟩	🟩										
Develop & pilot questionnaire			🟩	🟩								
Patient recruitment					🟩	🟩						
Disseminate survey					🟩	🟩						
Analysis							🟩	🟩	🟩			
Qualitative Research												
Ethics approval	🟦	🟦										
Community stakeholder meetings			🟦	🟦				🟦				
Develop topic guides				🟦								
Patient recruitment at collaborating centres					🟦	🟦						
Interviews of patients of collaborating centres						🟦	🟦	🟦				
Community focus group discussions							🟦	🟦				
Analysis								🟦	🟦	🟦		
Phase 3: Key Informant Study												
Develop topic guides								🟨	🟨			
Interviews with service providers and funders									🟨	🟨		
Analysis										🟨	🟨	
Develop intervention models											🟨	🟨
Dissemination				🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪

Project management

The co-PIs will have overall responsibility for the successful delivery of the proposed study, patient and public engagement, and scientific rigour. A first task will be to set up an advisory board that will meet twice a year to provide scientific advice, examine protocols, review instruments, and monitor progress. The board will comprise patient and public representatives, service providers, and academics. A project manager will have day-to-day responsibility for the study and will report to the PIs on a weekly basis. Each of the collaborating study centres will nominate a key worker to manage the study locally. A management team of all co-applicants will provide scientific, patient, and service delivery expertise, this team is complemented by international collaborators.

Public Contributor/Public Involvement

Engaging the patient community is a critical part of our research process. The study heavily focuses on the patient experience of the patient/provider relationship in HIV care services. Their input will provide excellent insight not only into the user determinants of outpatient attendance, but also the quality and design of services overall.

The UK community advisory board (UK-CAB) is a network of community HIV treatment advocates across the UK. It spans over 500 members from across 120 organisations. Their community representatives serve as a bridge into the mindset and opinion of its network members, providing a wide community point of view. Our study team has included a community representative from its inception, aiming to facilitate effective research design that will optimise community sensitisation and engagement. The representative has actively contributed to discussions on the feasibility of proposed designs and highlighted methods to refine the proposal. Their continued input will be sought across all the planning and implementation phases, particularly when planning a dissemination strategy.

As part of the research design, patient opinion will be sought within community focus groups, questionnaires and one-to-one interviews. UK-CAB representation will be pivotal when organising such focus groups and accessing those individuals whom are accessing community support but not medical care. Development and refinement of the research tools (the questionnaire and topic guide) will also be undertaken in consultation with UK-CAB. The content of these dialogues will be largely determined by the responses of patients themselves to self-administered questionnaires. In this way the study will be responsive to the needs and concerns of HIV patient populations. Their active involvement in the research will enable effective and productive outcomes.

The study will also set up an advisory board to work alongside the research team to oversee and consult on the process. The committee will comprise of lay representation from HIV positive individuals, UK-CAB, key community stakeholders, along with other clinicians and researchers working in the field.

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