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### **Co-designing health services for people with HIV who have multimorbidity: a feasibility study**

#### Abstract

##### Background

This study aimed to establish the feasibility of using Experience-based Co-Design (EBCD) to inform a new approach to the management of multimorbidity in people living with HIV (PLWHIV) and to identify priorities for future healthcare.

##### Methods

PLWHIV with >1 non infectious comorbidity and staff were recruited from five hospital departments and general practice. Staff and patient experiences were gathered through semi-structured interviews (staff), non participant observation, patient diaries and filmed patient interviews. A composite film of patient interviews was developed to illustrate emotional 'touchpoints' in the patient journey and priorities for service improvement identified by staff and patients in focus groups.

##### Results

Twenty-two PLWHIV and fourteen staff were recruited. Four patients completed a diary and 10 participated in a filmed interview. Touchpoints from the filmed interviews were: multiple appointments; repeating their story; high quality HIV care; lack of HIV knowledge in general healthcare; partnership with healthcare workers; shared medical records; communication and care co-ordination. Staff and patient priorities for future healthcare were: 1) medical records and information sharing, 2) appointment management and 3) care coordination and streamlining of services.

##### Conclusion

In light of the changing commissioning climate and the re-introduction of joint commissioning pathways, this study demonstrates that EBCD was feasible in the context of HIV and has shown that staff and patients can work together to identify evidence-based solutions to improve healthcare services for people with multimorbidity.

## Introduction

As a result of combination antiretroviral therapy (ART), HIV has become a chronic disease with an excellent prognosis(1). People with diagnosed HIV now have a near normal life expectancy, provided ART is initiated promptly and a high level of adherence to treatment is achieved and maintained(2). However, increasing numbers of people with treated HIV are being diagnosed with comorbid conditions associated with ageing, including cardiovascular, renal, hepatic, bone, neurological and pulmonary diseases(3) (4) (5) (6). Currently HIV care is usually provided in specialist clinics, with a focus on the prescription and management of ART. Despite excellent HIV outcomes, it is not yet known how healthcare for people living with HIV (PLWHIV) should be provided in the future to sustain these outcomes and to address the broadening spectrum of HIV infection as the cohort continues to age(7). There continues to be the need for an evidence based approach to future HIV healthcare delivery that incorporates multimorbidity models and develops in tandem with the recently formed Integrated Care Systems.

Increasingly healthcare providers are seeking to develop services in ways that are informed by patient experiences. Experience-based co-design (EBCD) is an established service improvement methodology that enables service users and providers to work closely together in the re-design of services with the explicit goal of improving experiences and the quality of care(8, 9). Whilst EBCD has previously been used to improve a number of healthcare areas including cancer services(10), emergency departments(11) and medical outpatients (12), to our knowledge it has not previously or to date been used in the development of services for PLWHIV or applied to people with comorbid conditions who are accessing a number of different healthcare services.

EBCD is typically conducted in six stages (13) (14):

1. Project set-up;
2. Gathering and understanding staff experiences through non participant observation and discovery interviews and feeding back the findings;

3. Filmed patient interviews which capture patients' journeys through healthcare services from the point of diagnosis onwards and enable patients to reflect together on their shared experiences
4. Bringing staff and patient participants together where the 'trigger film' is shown and used to jointly identify service improvement priorities;
5. Co-design groups comprised of staff and patients work on agreed improvement priorities;
6. Final Celebration and review event.

The filmed patient interviews at stage 3 are a distinctive component of EBCD and interviews are analysed in order to identify emotionally significant 'touchpoints' in the patient pathway (14). Emotional touchpoints have been defined as positive or negative emotional responses to care across the patient pathway(14). Individual patient films are edited to emphasise these touchpoints and develop a composite film which includes excerpts from all patient interviews. This composite film is later used as a trigger for change and service improvement(14).

EBCD has not previously been attempted in the HIV setting or with patients with multimorbidity. It was therefore not known if filmed interviews would be acceptable in this context. Moreover, there was no established pre-defined pathway for PLWHIV with additional long-term conditions.

This aims of this study were to: 1) determine the feasibility of using the EBCD approach with PLWHIV who had one or more comorbid condition and with staff from identified healthcare services (HIV, other medical specialities and general practice) involved in their care and 2) identify shared staff and patient priorities for future service redesign.

This project was intended to test feasibility and identify priorities for change and did not include co-design working groups (Stage 5) or a celebration and review event (Stage 6) that are usually undertaken in a full cycle of EBCD.

## **Methods**

This feasibility study was conducted at Brighton and Sussex University NHS Trust from October 2014 – July 2015. Ethics approval was obtained from the National Research Ethics Committee (Reference

14/LO/1479). Approval was obtained from the Sussex NHS Research Consortium to approach General Practitioners (GPs) in Brighton and Hove. The study was conducted in three phases: gathering patient and staff experiences (Stages 2 and 3); data validation in individual staff and patient groups (Stages 2 and 3) and a workshop with PLWHIV and staff to identify priorities for future service planning (Stage 4).

### **Gathering patient and staff experiences**

Staff and patient experiences of services were examined using non participant observations of clinical areas(9), patient diaries(15) and discovery interviews with patients and staff (16). Inclusion and exclusion criteria for staff and patients are shown in Tables 1 and 2.

#### *Non participant observations of clinical areas and consultations*

Six clinical areas (Cardiology, Renal, Rheumatology, Liver/Digestive Diseases, HIV and General Practice) were identified. Lead clinicians in each area were approached by the research team and written informed consent was obtained to undertake informal visits within the departments and to approach study-eligible clinical colleagues to participate in observed consultations. Hospital and clinic databases were then searched to identify HIV positive patients with one or more comorbidity who had appointments in one of the five hospital services during the subsequent three month period. Clinical staff providing care to HIV positive patients at one of these appointments were then approached and invited to participate in the study. Once written consent was obtained from staff, identified patients were approached by their clinicians and invited to participate. Appointments in General Practice were identified on an ad hoc basis by asking study-eligible patients whether they had upcoming appointments and inviting them to take part in an observed GP consultation. Consent was sought from staff and patients for the research team to observe up to two clinical consultations.

Non participant observations of the clinical areas were undertaken by two researchers (EN, EY) (10) . A notice was placed in waiting areas informing patients of the research and inviting them to wait

elsewhere if they did not wish to participate. The researchers sat in patient waiting areas and made written notes on the environment, patient flow and staff and patient interactions. Observation of clinical consultations was undertaken by EN. The process (e.g. structure of the consultation, medical notes, results, follow-up) and transactional elements (e.g. style of consultation, communication, relationship) of the consultation were documented at the time of observation.

#### *Patient diaries*

Patient diaries were utilised to capture a broader appointment experience in real time with minimal researcher influence (15). Clinic and hospital databases were searched for PLWHIV who had 2 or more booked appointments in any hospital setting over the subsequent 3 months. Eligible patients (Table 2) were then approached by an HIV healthcare worker involved in their care and invited to participate. Written informed consent was sought to keeping a diary of up to 4 appointments. Patients were asked to keep an electronic, audio or paper diary of their healthcare appointments over a 4-8 week period. Participants were provided with a template indicating the type of information to be recorded such as making and travelling to the appointment, experiences during the appointment, how the appointment fitted in with other appointments as well as their thoughts and emotions during these consultations. They were contacted every 1-2 weeks by telephone by a member of the research team to deal with any queries or concerns.

#### *Staff and patient interviews*

Interview guides were developed based on the analysis of the clinical observations and the diary study. Doctors and nursing staff were purposively selected for the discovery interviews from the six clinical service areas and invited to participate in a semi-structured digitally recorded interview. All staff interviews were conducted by an experienced qualitative researcher (EN) who was trained in EBCD, and took place in a private room within a hospital or clinic setting. Interviews were audio-recorded

and transcribed verbatim. Staff interview transcripts were labelled as HIV specialist or non HIV specialist to provide anonymity.

Patients who had one or more comorbidity were identified through searches of clinical and hospital databases, forthcoming appointments in the HIV clinic and through team and multidisciplinary meetings and invited to participate in a filmed interview. Those who agreed to participate gave written consent to their face being visible on film and for the film to be shared with other patients or healthcare workers for education or health service planning. Filmed patient interviews were undertaken in a private research room at the hospital by EN who was trained to conduct filmed interviews using a static camera. Following the interviews, each film was sent by courier to an external editor who produced an individual patient film. This was couriered to each participant, along with a consent form for release of the footage for use in a composite film.

### **Data analysis and validation**

Data analysis was undertaken on the clinical observation notes, patient diaries and staff and patient interview transcripts using inductive thematic analysis (17). This involved data familiarisation, initial coding, searching and reviewing themes and final definition and naming of themes. In addition to the thematic analysis, individual patient films were viewed by three researchers (EN, EY, VC) to identify emotional touchpoints in patients' experience(13). These touchpoints were used by the research team and film editors to develop a composite 30-minute film which illustrated each touchpoint using extracts from individual patient films(10, 14). Film participants were identified by pseudonyms.

Data validation was undertaken in separate patient and staff events. Patients were invited to attend a feedback session to watch the composite film and discuss the identified emotional touchpoints. A visual patient pathway was created by the research team and displayed at the meeting. Patients were asked to place sticky notes on the visual pathway to indicate their emotional responses and

experiences at each step of the pathway. The group then discussed, agreed and ranked their priorities for future service improvement.

The thematic analysis of staff interview transcripts was presented to staff participants at a separate meeting. Each identified theme was discussed and a list of priorities for the future development of services was agreed.

### **Workshop for setting future priorities**

Staff and patient participants were invited to take part in a joint stakeholder event, facilitated by EN. Key staff members from the six clinical areas, the appointments service manager, an IT systems manager, deputy chief nurse and the medical director were also invited. The group was presented with the findings from the staff interviews and then watched the composite patient film. After discussion of the findings, six groups were formed to work together to identify specific actions to address each of the priority improvement areas identified. The groups then re-convened to reach consensus on which priorities had the most potential to improve patient and staff experiences. The three most popular priorities were selected to be taken forward for future co-design work.

## **Results**

### *Patient engagement in EBCD and participation in filmed interviews*

In total 616 patient records were reviewed to identify eligible patients with a booked appointment in one of the designated hospital clinical areas. Seventy-seven patients (12%) met the study inclusion criteria (See Table 2). Of those, 8 were approached to participate in clinical observation, of whom 7 (87.5%) were recruited; 7 were approached for the diary study of whom 5 (71.4%) were recruited and 24 were approached for the filmed interviews of whom 15 (62.5%) were recruited. Reasons for declining to take part in the filmed interview were: not wanting their face to be visible because of



concerns about confidentiality or body image (6 (66.7%)) or lack of interest in the study (3, (33.3%)). Of the 15 patients recruited to the filmed interviews only ten participated. Reasons for this were a decline in physical health (1 patient was admitted to hospital; 1 patient became acutely unwell) and psychological health issues (bereavement (n=2); anxiety (n=1)). The overall response rate for recruiting to the filmed interviews was 41.6%. Although patients were consented for filmed interviews for education/ health planning purposes, some who participated (40%) expressed concern relating to public disclosure of their HIV status through internet or wider access to the film. This led to additional precautions to protect confidentiality such as the use of pseudonyms and couriers to transport the films.

Of the 22 patient participants, the majority were male (20; 90.9%); 20 (90.9%) were white British; 21/22 (95.4%) had an undetectable viral load, and a total of 110 comorbid conditions were identified (Table 3). The median age was 55 years (range 31 years – 91 years) and median time since diagnosis was 16.5 years (range 7-25 years).

Five of the 10 film participants (50%) attended the patient feedback meeting. Of all patient participants, 10/22 (45%) attended the final workshop. Reasons given for non attendance were ill health and other pre-planned commitments.

#### *Staff engagement in EBCD*

All ten staff who were approached for interview agreed to participate. Four were medical consultants from Renal, Rheumatology, Liver and Cardiology departments, 2 were GPs and 4 were HIV healthcare workers who had participated in joint clinics (3 medical consultants and 1 nurse specialist). One of the GPs provided a commissioned Local Enhanced Service for people with HIV.

For the clinical observations, 10 staff were approached, of whom 7 (70%) were recruited (3 did not respond to e-mails). Five staff (4 medical consultants and 1 nurse specialist from Renal, Cardiology, HIV and Rheumatology members (including 1 interview participant)) participated in 7 consultations;

two staff consented but could not participate because the patients were not contactable prior to the consultation appointment. No paired clinical observations took place in general practice. Staff recruitment was easier in areas where relationships had previously been established through joint working.

The joint co-design event was attended by 20 staff who had either participated in the clinical observations and/or interviews or who were representatives of the services provided in the study or the priorities raised.

### *Clinical Observations*

In total there were 12 hours of observations undertaken in 4 of the six clinical areas, of which 4 hours were observed consultations. The observation component was pivotal in building relationships with staff and understanding processes in the individual clinical areas. The observed clinical consultations highlighted issues with separate medical notes, different hospital and clinic numbers and increased researcher insight into the expectations of HIV patients in other departments.

### *Diary Study*

Of the five patients recruited to the diary study, 4 completed records of 20 (range 3-9) appointments over a 2 month period. One patient had repeated hospital admissions following recruitment and was therefore unable to participate. The diary study captured patient experiences across a wider range of healthcare settings, including unscheduled care. The diaries highlighted the importance of relationships with healthcare workers, the expertise of healthcare workers, access to appointments and inter-departmental communication. Negative experiences included the sheer volume of appointments and staff attitudes towards participants.

### *What were the key touchpoints for PLWHIV with comorbid conditions*

The analysis of the individual patient films, diaries and non participant observations identified 8 touchpoints, as described in Table 4. These were: managing multiple appointments; telling my story again; HIV services as a benchmark; expertise and knowledge; working alongside healthcare workers; shared medical records/results; communication and care co-ordination. The composite 30-minute film illustrated and was structured around these touchpoints.

### *Improvement priorities for staff and patients*

Staff identified three priorities for future service development for PLWHIV who have comorbid conditions: 1) Care co-ordination was identified as key to future service delivery to support PLWHIV with comorbidities to navigate across multiple services. 2) Access to shared medical records across primary, secondary and tertiary care was considered a priority to improve communication and continuity of care across healthcare teams. 3) The delivery of streamlined pathways across services and joint clinics was proposed to avoid duplication of investigations and promote easy access to shared test results and clinical expertise (Table 5). Patient participants identified six priorities (Table 5). These were care co-ordination; shared medical records and results; improved communication across health sectors; streamlining referral processes across specialities; managing multiple appointments and a holistic approach to managing multiple health conditions. At the workshop for setting future priorities staff and patients agreed the following shared priorities:

1. Medical Records and results systems / information sharing
2. Managing appointments
3. Care co-ordination and streamlining services

## **Discussion**

This study aimed to examine the feasibility of using EBCD to assist in the planning of future services for people with HIV who have comorbid conditions. The findings demonstrate acceptable staff and

patient engagement with the process and an alignment of staff and patient priorities for future service development. They indicate that the EBCD methodology can be applied to the HIV setting and across a comorbid disease pathway.

The aim of EBCD is to capture the 'seldom heard voice' of the patient(10, 13), and one of the key questions in this study was whether PLWHIV would choose to participate in a filmed interview. Although some modifications were made to the traditional form of EBCD, minimal difficulties were encountered in recruiting patients who were willing to be filmed for educational and health service planning purposes. However, there was some reservation about the distribution of the films to the wider public domain.

The concurrent diary study provided a unique opportunity for patients to record their experiences in real time. While the themes identified in the diaries were similar to those identified in patient interviews, patients' experiences of healthcare reported in the diaries were generally more negative and may represent a more accurate lived experience.

The patient voice has historically been integral to the development of HIV services and there are many examples of effective HIV patient advocacy groups and patient involvement models(18) (19) (20). Studies on patient experience and values in HIV care are prevalent across both grey and published literature (21-24). Health services research by the Kings Fund drew upon the experiences of both healthcare workers and patients to inform recommendations for future HIV care provision(7). This EBCD study adds to the HIV co-production field a systematic service design approach to capturing staff and patient experiences of providing and receiving care within the context of multiple comorbid conditions and using these experiences to define joint priorities for service improvement. The composite film was a powerful tool for generating discussion on the patient experience. In the continued absence of a defined and evidence based model of HIV care that can sustain current treatment outcomes and quality of care, EBCD can be applied at a local service level to identify and co-design improvements in care and has the potential to inform the design principles for a national

model of care for PLWHIV who have more complex needs. Although this study was completed 6 years ago, there has been no cohesive change in the way that HIV healthcare is commissioned for PLWHIV who have comorbid conditions. The EBCD methodology and priorities for future HIV healthcare identified in this study could continue to be of value in current and future service configuration.

Previous studies using EBCD have focussed on single disease areas or departmental pathways (10-12). This research expanded those parameters by involving six different departments involved the care of PLWHIV who have comorbid conditions. This involved developing a multimorbid disease pathway that incorporated access to and care provided by number of clinical services. . Identifying eligible patients with comorbid conditions was initially cumbersome due to a lack of coding systems for multimorbidity of at that time.

This feasibility study was conducted in a single site with a caseload of predominantly men who have sex with men. Research with more diverse caseloads may result in different service improvement priorities and this highlights the importance of identifying needs at a local as well as at a national level. In conclusion, the findings of this study suggest that EBCD methodology is acceptable to PLWHIV with comorbid conditions and staff from across the patient pathway. Lessons learned from utilising this methodology could facilitate the wider use of EBCD to implement service improvements in other HIV settings. Patient and staff priorities for future HIV healthcare were focussed on a joined up approach to care, information sharing and the streamlining of services across HIV, General practice and other specialist areas.

3575 words

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Table 1: Inclusion criteria for staff

| <b>Staff inclusion criteria for clinical observation / discovery interviews</b>   |
|---|
| <ul style="list-style-type: none"> <li>• Worked in current clinical area for &gt; 12 months</li> <li>• Involved in the care of HIV patients in joint clinic or providing non-HIV care to HIV patients</li> <li>• Willing to participate in observation of consultation with an HIV positive patient or discovery interview</li> </ul> |

Table 2: Inclusion/Exclusion criteria for patients

| <b>General inclusion criteria for patients</b>  |  |  |
|---|--|--|
| <ul style="list-style-type: none"> <li>• 16 years of age or over</li> <li>• HIV +ve for &gt; 12 months</li> <li>• At least 1 or more active non-infectious chronic co-morbid condition</li> <li>• Ability to participate in the English language</li> </ul> |  |  |
| <b>Inclusion criteria for observed consultation</b>   | <b>Inclusion criteria for diary study</b>  | <b>Inclusion criteria for filmed interviews</b>  |
| Has an appointment with a GP or in designated clinical areas (HIV, Liver, Renal, Cardiology, Rheumatology) in the following 3 months  | Has an appointment arranged with a GP or hospital specialist over the following 3 months | Willing to consent to face-to-face filmed interview for use in education and service improvement |
| <b>Exclusion criteria</b>   |  |  |
| <ul style="list-style-type: none"> <li>• Current inpatient admission (or admission within the past 2 weeks)</li> <li>• Prognosis of less than 3 months</li> </ul>   |  |  |



Table 3: Comorbid conditions in the 22 patient participants

| Comorbid conditions          | Numbers identified via clinical summaries   |
|------------------------------|---|
| Rheumatological              | 15  |
| Cardiovascular               | 13  |
| Diabetes and endocrine<br>13 | Diabetes 6 Cushings 1. Hypogonadism 2.<br>Addisons 1. Lipodystrophy 2. Hypothyroid 1.   |
| Mental Health                | 12  |
| Renal                        | 10  |
| Respiratory                  | 10  |
| Neurological                 | 8   |
| Liver                        | 5   |
| Orthopaedic                  | 4   |
| Cancer                       | 2   |
| Other                        | Haematological 3. Urinary/prostate 5.<br>Dig Diseases 5. Ophthalmic 4. Leishmaniasis 1. |

Table 4: Touchpoints from the filmed interview data

|   | <b>Touchpoint</b>                    | <b>Description</b>   |
|---|--------------------------------------|--|
| 1 | Multiple appointments                | A prominent theme was the sheer number of appointments that patients had in different departments and healthcare settings. This presented logistical challenges for patients attending appointments or in trying to get appointments rescheduled.  |
| 2 | Telling my story again               | When seeing a new healthcare professional, patients found it challenging to go over their HIV story again and many dreaded a new referral for this reason. Some patients found it emotionally difficult to re-live their HIV diagnosis, for others, it was tediously repetitive.   |
| 3 | HIV services as the benchmark        | Patients reported receiving a high quality of care in HIV services that provided a benchmark for their expectations of other healthcare services. Many saw the HIV service as a safe haven and a place to go when they were unsure or unable to sort out a health problem.   |
| 4 | Expertise and Knowledge              | Patients highly valued the expertise and knowledge of their HIV team and often looked to them for advice in dealing with non-HIV conditions. This was often based on a lack of confidence in non-HIV healthcare workers who they saw less frequently. Several patients reported that they delayed seeking healthcare until their next appointment at the HIV clinic. |
| 5 | Working alongside healthcare workers | Many of the patients highlighted the value of working in partnership with their healthcare workers and a joint approach to tackling health problems. Patients contrasted this approach with the approach of some non-HIV services where they felt they were not included in decisions about their care.  |
| 6 | Shared medical records /results      | Patients and staff groups spoke of the challenges of having separate medical records and how this impacted on staff having up to date information about them or in joining up their medical history. Repetition of blood tests and separate results systems was also a cause of frustration.   |
| 7 | Communication                        | The importance of communication across healthcare services was a key factor in joining up services and patients had mixed experiences of this.   |
| 8 | Co-ordination of care                | Co-ordination of care and streamlining of services was a dominant touchpoint for patients and where this existed, patients felt hugely relieved. For most, lack of co-ordination of care resulted in repetition, unnecessary appointments and feeling overwhelmed.   |

Table 5: Patient and Staff Priorities for future service provision

| <b>Patient and Staff Priorities</b>   |   |
|---|---|
| <b>Patients</b>   | <b>Staff</b>  |
| <ol style="list-style-type: none"> <li>1. Care coordination</li> <li>2. Shared medical records and results</li> <li>3. Communicating health information</li> <li>4. Streamline referral process to specialist</li> <li>5. Managing appointments</li> <li>6. Health conditions not treated in isolation</li> </ol> | <ol style="list-style-type: none"> <li>1. Care coordination model</li> <li>2. Access to updated patient medical record (including drug interactions) across primary, secondary and tertiary care</li> <li>3. Streamline pathways for comorbid conditions to prevent duplication of screening and tests</li> </ol> |