

Speaker Name	Statement
Eileen Nixon	No interests to declare
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Patients and staff priorities for future care of people with HIV with have comorbid conditions

This study was part of an NIHR Programme Development Grant that aimed to inform the development of HIV services to meet the needs of an ageing population

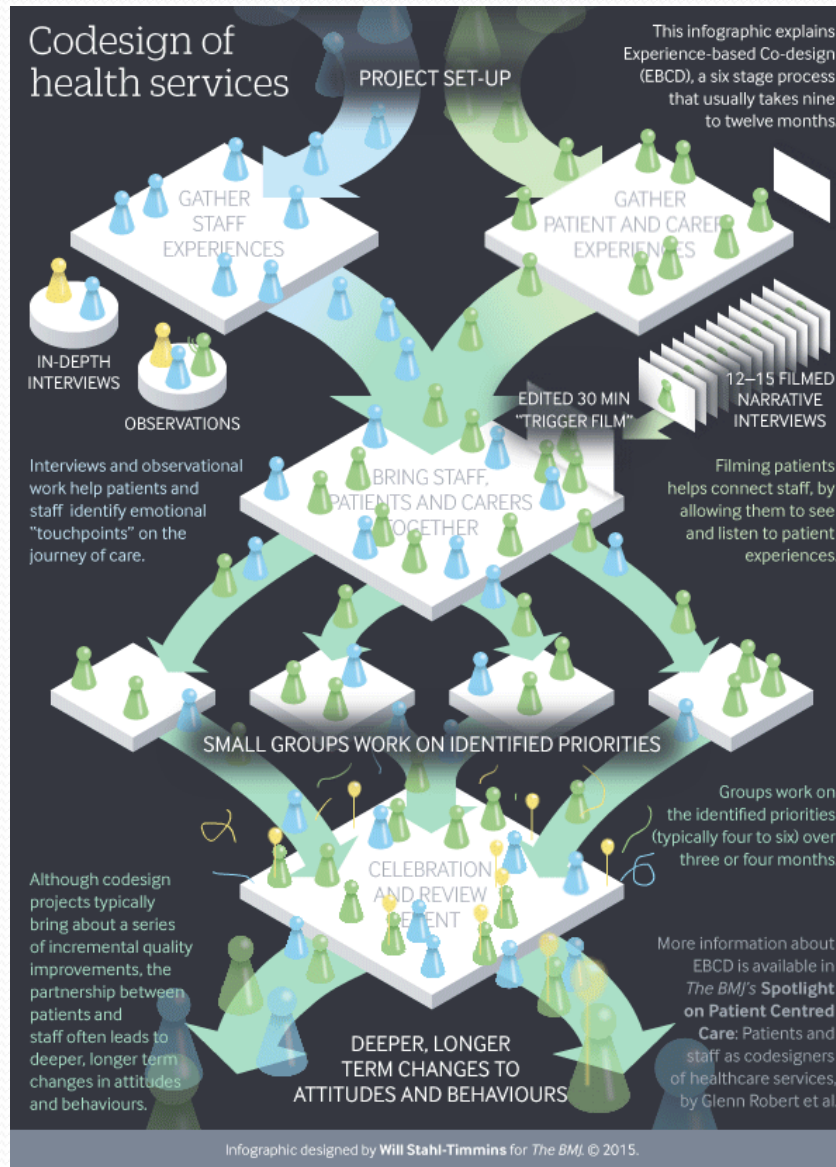
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Aim of the study

To pilot co-design methodology for people with HIV in order to:

- To understand the experiences of people with HIV who have comorbid conditions
- To identify priorities for future service planning and co-design

Experience based co-design methodology



<http://static.www.bmj.com/content/bmj/350/bmj.g7714/F1.medium.gif>.

Method

Observation of clinical areas

Diary study



Observations and staff interviews focussed on the following services:

- Cardiology
- General Practice
- HIV
- Liver
- Renal
- Rheumatology



Staff Interviews



of 1-1 consultation



Filmed patient interviews

Selection

- **Diary Study**

 - Referral letters from HIV clinic to any secondary care service*

- **Observations in specified disease/service areas**

 - Search key terms in HIV clinical letters database*

 - Reporting codes (UKCHIC and Sophid)*

 - Existing databases (Liver, Cardiology, Renal)*

 - HIV blood and HIV doctor appointment lists*

 - Hospital database for appointments*

- **Staff interviews**

 - Purposive selection through engaging with service areas*

- **Filmed patient interviews**

 - Databases above*

 - Team meetings / community teams*

Data analysis and validation

- Thematic analysis¹ of diaries, observations, staff interviews and filmed patients interviews
- Analysis of key defining moments or emotional touchpoints for filmed interviews
- Undertaken by 3 of the study team
- Validation through patient and staff feedback meetings

¹ *Braun and Clarke 2006*

Patient Recruitment

- Diary



- 5 recruited
- 4 completed
- 1 didn't complete for health reasons

- 1-1

- 7 paired interviews
- 2 HIV
- 2 Rheumatology
- 2 Renal
- 1 Cardiology



- Film



- Approached 24
- Recruited 15¹
- Participated 10

- Decliners 9/24

- 6/9 did not want face to be visible (2 female)
- Most would consider audio
- 3 not interested

¹ Reasons for not participating, 2 unwell, 1 anxiety, 2 bereavement

Comorbid conditions	Numbers identified via clinical summaries
Rheumatological	15
Cardiovascular	13
Diabetes and endocrine 13	Diabetes 6 Cushings 1. Hypogonadism 2. 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. Dig Diseases 5. Ophthalmic 4. Leishmaniasis 1.

22 patients with 110 conditions

Staff recruited

	Allied Specialist	General practice	HIV joint clinic staff	Total
Doctor	4	2	3	9
Nurse	1*	-	1+	2
Total	5	2	4	11

*Plus 2 informal visit with nursing teams in allied specialities
+ Plus 1 informal visit with HIV nursing team

Feedback meetings

Brighton and Sussex
University Hospitals
NHS
NHS Trust

YOUR EXPERIENCE MATTERS:

Co-design diary dates

Event 1: Staff feedback event

Feedback on staff experience of looking after people with HIV who have co-morbid conditions and identifying key priorities for future service development

25th June 5:15-7:30

Lecture Theatre – Audrey Emerton Building (changed from Sussex House)

Sandwiches, snacks and drinks will be provided

Please RSVP to Eileen Nixon eileen.nixon@bsuh.nhs.uk

YOUR EXPERIENCE MATTERS: HIV CO-DESIGN STUDY



Event 2: Patient Feedback Event

This is the first of two events for patient participants. At this event, patients who participated in the film will watch the film together and discuss the key priorities for change in preparation for the joint feedback session with staff on 20th July.

When: 15th July 5:00-7:30

Where: Seminar Room 4, Audrey Emerton Building

Food and drinks will be provided

Please RSVP to Eileen Nixon eileen.nixon@bsuh.nhs.uk

Brighton and Sussex
University Hospitals
NHS
NHS Trust

YOUR EXPERIENCE MATTERS



Staff and patient events for HIV co-design study

Event 3: Joint Feedback Event

At this event patients and staff will feedback on their experiences of receiving and delivering healthcare services for people with HIV who have co-morbid conditions and agree shared priorities for change. This meeting will be open to all study participants as well as other healthcare workers, senior Trust managers and commissioners.

Monday 20th July

5:30-8.30 including food and drinks

Audrey Emerton Building next to Sussex Eye Hospital

Please RSVP to Eileen Nixon eileen.nixon@bsuh.nhs.uk

Touchpoints from filmed interviews

Multiple appointments

Medical records

Telling their story again

Quality HIV care

Expertise and knowledge

Communicating health information

Care co-ordination

Working alongside healthcare workers

Master themes from staff interviews

- Paradigm shift
- Patient engagement with non-HIV services
- Barriers to looking after people with HIV who have comorbid conditions
- Facilitators for looking after people with HIV who have comorbid conditions

Patient and Staff Priorities

Patients

1. Care coordination
2. Shared medical records and results
3. Communicating health information
4. Streamline referral process to specialist
5. Managing appointments
6. Health conditions not treated in isolation

Staff

1. Care coordination model
2. Access to updated patient medical record (including drug interactions) across primary, secondary and tertiary care
3. Streamline pathways for comorbid conditions to prevent duplication of screening and tests

Agreed areas for co-designing a new model of care

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

3 minute film will be inserted here

Lessons learned from the pilot

- Need to develop databases of people with comorbid conditions
- Include and involve carers in the study
- Timescales need to factor in:
 - conflicting staff schedules can affect engagement
 - small volume of hospital appointments in the specified service areas
 - Patients becoming unwell during the study period

Conclusions and next steps

- Experience based co-design methodology was acceptable in the HIV setting and patients and staff were engaged
- Pilot identified 3 key areas for co-designing services for people with HIV who have co-morbid conditions
- May be relevant to other groups with multi-morbidities
- **Next Steps**
 - Work with staff and patients to address the co-design priorities
 - Further research using co-design methodology in other HIV settings

References

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