<table>
<thead>
<tr>
<th>Speaker Name</th>
<th>Statement</th>
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<tbody>
<tr>
<td>Eileen Nixon</td>
<td>No interests to declare</td>
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<tr>
<td>Date</td>
<td>June 2017</td>
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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

Eileen Nixon, Vanessa Cooper, Elaney Youssef, Glenn Robert, Sara Donetto, Angelina Namiba, Robert Fieldhouse, Claire Foreman, Nicky Perry, Caroline Sabin, Naomi Fulop, Juliet Wright, Martin Utley, Nick Freemantle, Alec Miners, Helen Smith, Martin Fisher
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

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 analysis\(^1\) 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 15\(^1\)
  - 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
<table>
<thead>
<tr>
<th>Comorbid conditions</th>
<th>Numbers identified via clinical summaries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatological</td>
<td>15</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>13</td>
</tr>
<tr>
<td>Mental Health</td>
<td>12</td>
</tr>
<tr>
<td>Renal</td>
<td>10</td>
</tr>
<tr>
<td>Respiratory</td>
<td>10</td>
</tr>
<tr>
<td>Neurological</td>
<td>8</td>
</tr>
<tr>
<td>Liver</td>
<td>5</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>4</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
</tr>
</tbody>
</table>

22 patients with 110 conditions
### Staff recruited

<table>
<thead>
<tr>
<th></th>
<th>Allied Specialist</th>
<th>General practice</th>
<th>HIV joint clinic staff</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctor</strong></td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td><strong>Nurse</strong></td>
<td>1*</td>
<td>-</td>
<td>1*</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5</td>
<td>2</td>
<td>4</td>
<td>11</td>
</tr>
</tbody>
</table>

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

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@bshs.nhs.uk

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@bshs.nhs.uk

Event 3: Joint Feedback Event

Staff and patient events for HIV co-design study

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@bshs.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

<table>
<thead>
<tr>
<th>Patients</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Care coordination</td>
<td>1. Care coordination model</td>
</tr>
<tr>
<td>2. Shared medical records and results</td>
<td>2. Access to updated patient medical record (including drug interactions) across primary, secondary and tertiary care</td>
</tr>
<tr>
<td>3. Communicating health information</td>
<td></td>
</tr>
<tr>
<td>4. Streamline referral process to specialist</td>
<td>3. Streamline pathways for comorbid conditions to prevent duplication of screening and tests</td>
</tr>
<tr>
<td>5. Managing appointments</td>
<td></td>
</tr>
<tr>
<td>6. Health conditions not treated in isolation</td>
<td></td>
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</table>
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


Piper D, Iedema R, Gray J, Verma R, Holmes L, & Manning N Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study

