

Patient Reported Outcome Measures (PROMs) HIV & Ageing

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Background:

- Recent advancements in developing HIV drugs have successfully kept people's immune systems healthy with fewer side effects and fewer pills.
- Despite the tremendous improvements enabling most people to live long and healthy lives with HIV, patients who are ageing with HIV are increasingly experiencing many clinical and social challenges relating the HIV condition.
- Evidence of patients experiencing a complex set of barriers particularly true for black Africans who are ageing with HIV

Issues Patients Aging with HIV experience

In the UK, over 101,200 people are living with and many of these patients fall in the over 50s age cohort. More than a third (38%) of people accessing HIV care aged 50.

Patients who are ageing with are increasingly experiencing many challenges relating to co-morbidities as well as other social issues.

- Lack of effective communication with clinicians,
- Lack of effective assessments for co-morbidities ((e.g. bone density, cardiovascular, renal, liver, malignancies)
- HIV stigma, discrimination (self stigma, community, clinical settings)
- Deprivation and social isolation, poverty, lack of social safety nets,
- Low clinical literacy levels
- Problems managing co-morbidities associated with HIV and Ageing among others.
- Lack of effective engagement with clinicians

PROMs

What are PROMs? (i)

- **Patient Reported Outcomes (PROs):** are evaluation made by patient without any input from their family, carers and healthcare workers.
- **Patient Reported Outcomes Measures (PROMs):** are tools used to capture PRO information directly from patients

PROMs

PROMs aid better clinical outcomes for patients

- They promote better patient involvement in care decisions;
- Improves relationships and communication between patients and professionals
- Can improve treatment adherence

At an individual level, PROMS can help identify and monitor what matters to patients

At service level, PROMS ensure that care is directed and measured around those outcomes, thereby promoting quality and equity.

Good practice required that patients should be involved in the development of PROMs to ensure that they reflect patient perspectives and needs.

Why are PROMS Important in HIV Care?

- **PLWHIV can experience a range of problems and concerns in their treatment and care.**
- **Careful management - central to helping people to live well with HIV, maintaining clinic attendance and treatment adherence.**
- **HIV healthcare professionals sometimes miss problems and concerns of PLWHIV, if not raised by the person themselves.**
- **PLWHIV have multidimensional concerns requiring person-centred care. Routine use of PROMs improves outcomes.**
- **PROMs represent an important part of assessing whether PLWHIV and other healthcare professionals are improving the symptoms reported by their patients**

However....

- **The standard nature of most of the PROMS in use do not take into account the various challenges that patients who are ageing with HIV experience**
- **A review of PROMs currently used 5 clinics in London show that they are largely standardised and are not specific to the needs of patients Ageing with HIV**
- **Mostly academic and the way they are framed usually ignore issues that rank highest in everyday life for patients e.g immigration, financial hardships, isolation, stigma, stress, depression, social life among others.**
- **Patients with low literacy levels sometimes struggle to complete the PROMs and this means that the practitioner may not know how the patient actually feels.**

PROMs in Practice

PATIENTS

- Patients register and complete their first assessment on any device at home or in clinic
- Reminder emails prompt the patient when their next assessment is due
- A personalised dashboard allows users to track their results over time and understand the ongoing benefits of treatment

CLINICIANS

- Data is made available to clinicians in real-time
- Individual patients' results can be viewed, analysed and used to inform insight-driven clinical decisions
- Data can be filtered, aggregated and analysed to compare cohorts and identify opportunities to improve

PROMs in Practice

MANAGEMENT

- **Meaningful variation in outcomes can be identified by comparing differences between sites, clinicians and treatment outcomes**
- **Insight can be used to increase value by focusing improvement efforts and reducing less effective treatments**
- **Barriers or challenges, could be identified with patient input**

NB: This is usually repeated over a period of time

NAME John Q. Sample DATE _____

 Over the last 2 weeks, how often have you been bothered by any of the following problems?

| | | Not at all | Several days | More than half the days | Nearly every day |
|---|--|------------|--------------|-------------------------|------------------|
| 1 | Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2 | Feeling down, depressed, or hopeless | 0 | 1 | 2 | 3 |
| 3 | Trouble falling or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4 | Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5 | Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6 | Feeling bad about yourself - or that you are a failure or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7 | Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8 | Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 9 | Thoughts that you would be better off dead, or of hurting yourself in some way | 0 | 1 | 2 | 3 |

 add columns: +

 TOTAL:

| | | | |
|----|--|----------------------|-------------------------------------|
| 10 | If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? | Not difficult at all | <input type="text" value=""/> |
| | | Somewhat difficult | <input checked="" type="checkbox"/> |
| | | Very difficult | <input type="checkbox"/> |
| | | Extremely difficult | <input type="checkbox"/> |

Task in Groups of 2

3 minutes to list the benefits of PROMs for

Patients:

Services:

Benefits of PROMs

For PLWH:

- Enable patient centeredness and empower PLWH
- Help PLWH raise concerns, and feel heard and valued, and share sensitive information
- Help PLWHIV to build resilience and self confidence
- Encourage referrals for additional support
- Reduce assumptions, establish an individual baseline and monitor changes over time
- Help get to know new patients
- Go beyond adherence and viral load

For Services:

- Tailor service to specific needs of population
- Understand changing picture of HIV
- Improve efficiency and reduce inappropriate service use
- Reassure and build confidence in clinicians
- Justify current spending

Example; AAF Rethinking PROMs

Interviews:

- PLWHIV,
- Healthcare professionals (medical, nursing, social work, pharmacy, mental health)
- HIV Commissioners.

(key themes captured and recorded)

Focus Group Meetings:

- with PLHIV & Professional (Consultation on the key themes-what is missing, etc)
- Consultations:
- HIV professional bodies e.g. BHIVA in the UK;
- Patient Representative Bodies e.g. UKCAB etc

(Consultation on the key themes- how the PROMs be improved?, What is missing, etc.)

- Validation, Endorsement

Group Work

What will be the key Questions/feedbacks - will each parties want to be included in a PROMs:

- **PLWHIV**
- **Healthcare professionals (medical, nursing, social work, pharmacy, mental health)**
- **HIV Commissioners.**