

The forgotten few: the challenge of opting out of ART

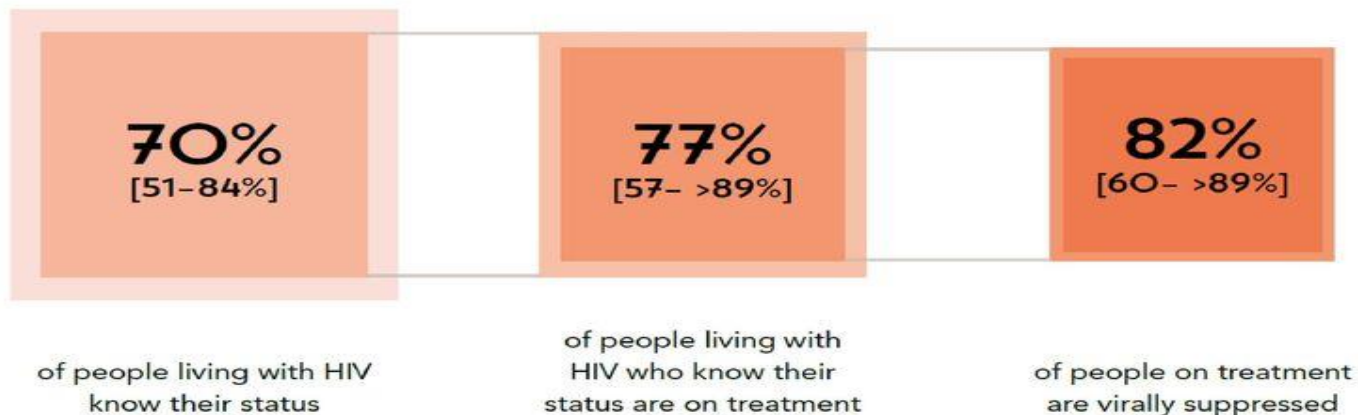
Intentional non adherence **Vs** non intentional non adherence (NICE CG76)

- Review 90-90-90 targets
- Why opt out?
- Case study x 2
- Propose best practice model

90-90-90



CLOSING IN ON A FAST-TRACK TARGETS



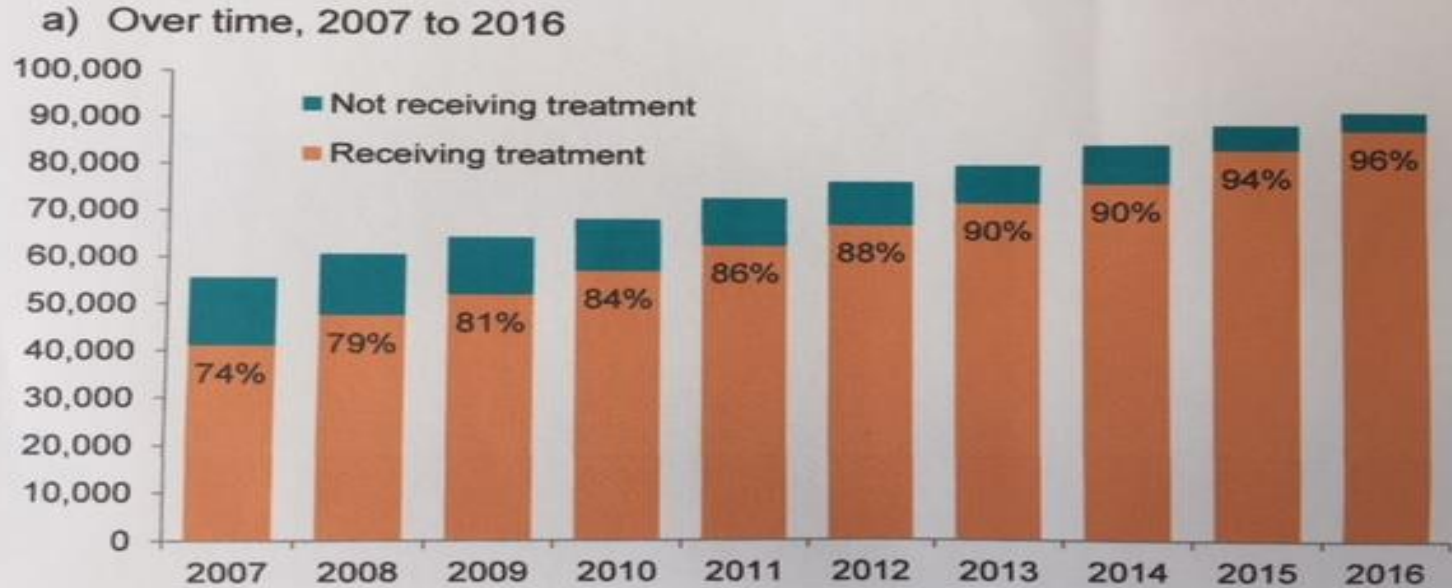
PROGRESS TOWARDS THE 90–90–90 TARGETS, GLOBAL, 2016

Source: UNAIDS special analysis, 2017; see annex on methods for more details.

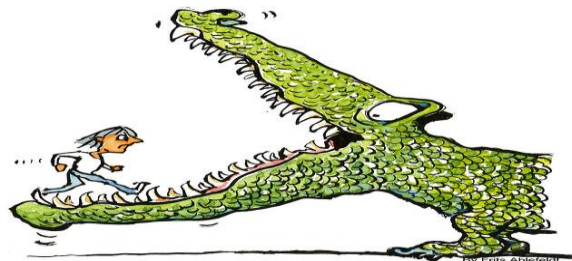


Liverpool HIV community nursing
June 2018

Figure 15: ART coverage among people accessing HIV specialist care, UK



Our challenge



- ▶ WHO 23% (UNAIDS 2017)
- ▶ UK 4% (PHE 2016) 78,900 people diagnosed HIV in England, 3156 of those are not taking ART (PHE 2016)
- ▶ LCC 16% not 8% = opting out

Caseload review methodology

- ▶ A caseload/documentation review & 2 team discussions to identify & explore reasons for opting out of ART
- ▶ Team reflected on past cases to identify key components of a best practice model

Results

- ▶ Associating tablets with HIV related stigma
- ▶ Adoption of personal belief systems such as religion, alternative therapy, traditional medicine, shamanism, conspiracy theorists
- ▶ Slow progressors who feel well
- ▶ Denial
- ▶ Fear of side effects & medication toxicity
- ▶ Medication fatigue

Reasons why PWH opt out of ART

- ▶ Invincibility/optimistic bias
- ▶ Treated depression/ low self-esteem
- ▶ Social isolation with no incentive for good health and well-being
- ▶ Cyclical periods of good/poor health coinciding with starting/stopping ART
- ▶ Desire to survive but not with HIV
- ▶ The need to exercise control
- ▶ Punishment to significant others

Case study 1

- ▶ 38 year old female Δ 10 years
- ▶ Opted out due to religious belief “ If I take ART it shows I don’t have faith in God”
- ▶ Years of progressive self neglect, home unsanitary, rodents, profound hoarding behaviours
- ▶ Assessed consistently as having mental capacity
- ▶ H/O intermittent crack cocaine/solvent abuse
- ▶ Referred to community nurses Oct 2017 PCP
- ▶ Maintained contact via home visits fortnightly
- ▶ Jan 2018 community nurses escorted her to clinic, frail, underweight, poor mobility, hypotensive
- ▶ Admitted to hospital and discharged five days later
- ▶ CD4 count 1 V/L 2.5 million
- ▶ Anaemic
- ▶ Clinically dying

- ▶ Social services refused to initiate care package as property deemed unsafe
- ▶ Refused further hospital admission
- ▶ Community nurses referred to hospice
- ▶ Admitted the next day for palliative care
- ▶ Two days into admission agreed to start ART due to fear of imminent death
- ▶ Rapid response to ART 9,000 Feb undetectable March CD4 90
- ▶ Discharged 6 weeks later into new ground floor flat
- ▶ 4 months later remains on ART & undetectable

Case study 2

- ▶ 22 year old male Δ 2004 age 10/vertical transmission/informed age 12
- ▶ H/O intermittent adherence? Referred a few times declined engagement
- ▶ PCP x 3
- ▶ Opted out of ART
- ▶ Referred Sept 2016 by consultant/home visits commenced
- ▶ CD4 12 V/L 680,000
- ▶ Ongoing conflict between pt. & mum
- ▶ Novel approaches to support adherence

- ▶ Discussed DOT at MDT started Dec 2016
- ▶ Jan 2017 CD3 V/L 174
- ▶ Focus remained on ART/undetectable
- ▶ End of Jan viral rebound 1.5 million
- ▶ Professional conflict re referrals
- ▶ Admitted shortness of breath beginning Feb 2017
- ▶ Refused ART
- ▶ March 2017 requested palliative care referral from ward ? DNR form completed
- ▶ Ongoing capacity assessments
- ▶ Consistently refused ART
- ▶ MDT involvement continued/family despair
- ▶ Passed away 21 March 2017

Key components of a good practice model



Opt out
of ART

- Timely/ongoing MCA
- Robust MDT working & communication (consent)
- Advocacy/group consultation appts
- Communicate prognosis and document
- Completion of palliative / end of life documents i.e. Preferred Priorities of Care, Advanced directives, DNR & DS1500
- Maintain engagement (home visits/ phone/clinic appts)
- Flexible approach to tailored care
- Timely referrals to palliative care (1 year before anticipated death)
- Shift emphasis from ART to individual priority issues (NICE 2009)
- Support significant others (conflict)
- Support change of mind (plan B)
- Clinical supervision/resilience

The Five Principles of the Mental Capacity Act

1. **Assumption of Capacity:** A person must be assumed to have capacity unless it is determined they lack capacity.
2. **Provide Help and Support:** A person is not to be treated as unable to make a decision before all reasonable steps have been taken to help and support them without success.
3. **Unwise Decisions:** A person is not to be treated as lacking capacity just because they make an unwise or eccentric decision.
4. **Best interest:** Any action, or decision made under the Act on behalf of a person who lacks capacity must always be done in their best interest.
5. **Least Restrictive:** Any action, or decision made on behalf of a person who lacks capacity should be done in the least restrictive manner of the person's basic rights and freedoms.

Other factors that may affect capacity to make a decision include:

- **Lack of information** – make sure that any information relevant to the decision is provided in a format that the person can understand.
- **Pressure** – carers or other family members may sometimes exert undue pressure when the person being cared for is capable of making their own decisions or where expert help may assist them to do so. Further advice should be sought through your line manager.
- **Lack of trust** – a person may feel anxious about dealing with staff from interested agencies so ensure that they have access to independent support advice or advocacy in these circumstances.

Acting in Best Interest

- Consideration must be given as far as reasonably ascertainable to the person's past and present wishes and feelings, their beliefs, values and any other factors that would be taken into account if the person had capacity.
- Consider if practicable and appropriate the views of people who have formally or informally been involved with, or named by, the incapacitated person e.g. relatives, carers and friends of the service user/patient etc.
- Are there any written statements made whilst the service user/patient had capacity must also be taken into account (whether registered as an advance decision or not)?
- Any other information relevant to this decision.
- Does the individual need the support of an **IMCA**?

How to document the assessment of capacity and best interest decision process

The process of arriving at the decision made must be recorded in the patient's file with all supporting documentation in relation to how decisions were made. Person centred care plans and risk assessments will be required.

Support tools are available on the LCH Intranet site.

For additional support contact the Safeguarding Adults Team on the Duty Line on 07717 576890.

Conclusion

- ▶ Nurses have a key role to engage/manage/support/review to assess changing needs, priorities and wishes
- ▶ The right to opt out of ART should be respected (GMC)
- ▶ A best practice model may improve patient outcomes and experience
- ▶ MDT communication is crucial
- ▶ A dignified symptom controlled death carries equal importance to ART if it is a competent, informed, individual decision

References

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- ▶ National Health Service 2009 Advance Care Planning, Available www.endoflifecare.nhs.uk/eolc/acp.htm (last accessed 18 October, 2009)
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