Finding the lost-to-follow-up: A Peer-Led Data Linkage and Case-Finding Model to Support Hepatitis C Elimination

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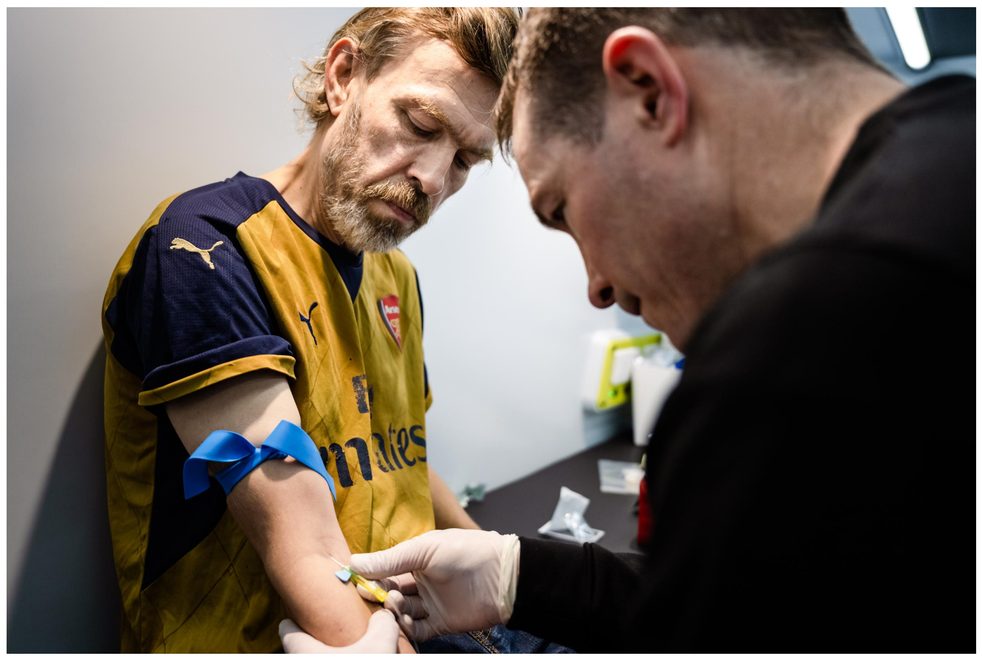
INTRODUCTION

- A significant number of individuals with a recorded diagnosis of Hepatitis C have no documented evidence of treatment completion or cure.
- Fragmented healthcare records, population mobility, duplicate NHS records and incomplete surveillance data make it difficult to determine whether individuals are truly lost to follow up (LTFU).
- Return2Care (R2C) Find&Treat (F&T) is a London-based, peer-involved, multidisciplinary infectious disease NHS service working across the spectrum of inclusion health groups.
- We describe a systematic, peer-led case-finding approach to identify individuals referred to F&T as LTFU who require re-engagement with care.

METHODS

- Find&Treat R2C worked with NHS England to develop an 'Identify, Contact, Engage' (ICE) process to identify patients lost to follow up through data validation, record linkage and outreach.
- HCV testing and treatment records of patients referred to R2C were cross-referenced against treatment databases, electronic patient records, primary care systems and mortality records. Missing identifiers were retrieved where possible and duplicate records removed. For patients without a confirmed outcome, additional searches were undertaken using healthcare, homelessness and other datasets.
- Patients with unresolved outcomes underwent follow-up through peer-led telephone contact and intelligence-led street outreach.





Photos. Left. James Rock, senior peer practitioner. Photo by Oliver Wolff

Right. Staff at work on the Find&Treat van. The Return2Care Find&Treat team/

RESULTS

Identify

1. R2C received LTFU referrals

Referrals were cross-referenced against:

- Treatment databases
- Electronic patient records
- Primary care records
- Mortality records

2. Peer-led desk searches and cross-system data linkage identified:

- Duplicate records
- Out-of-date contact information
- Out-of-date healthcare & treatment records
- Deaths and embarkation

3. LTFU dataset refinement -

- Surveillance lists updated
- Genuine LTFU cases were prioritised for re-engagement activities

Contact

4. Peer-led phone calls or messages

- Contact made with individuals diagnosed with hepatitis C who have an unknown or uncertain treatment outcome

5. Intelligence-led street outreach

- Outreach to find individuals diagnosed with hepatitis C who are not contactable by phone

Engage

6. Peer-led street outreach

- Outreach to streets, homeless hostels, day centres and other venues to re-engage individuals diagnosed with hepatitis C who require treatment confirmation

7. Re-test, treat and test of cure

CONCLUSIONS

Many patients classified as LTFU can be successfully traced through improved data linkage and cross-system collaboration.

A structured case-finding approach combining data integration, multidisciplinary working and peer-led outreach can improve the accuracy of LTFU lists, reduce unnecessary follow-up activity and focus resources on individuals who genuinely require re-engagement with care.

These approaches may support HCV elimination programmes and the management of other long-term infectious diseases.

KEY MESSAGE

Cross-system data integration plus peer-led outreach enables accurate identification and re-engagement of individuals diagnosed with hepatitis C who genuinely require re-engagement

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