

# What is the acceptability of using phylogenetic data in clinical and public health practice?

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## INTRODUCTION

- The use of phylogenetics to guide HIV public health interventions (PHI) is a growing area of interest and has been implemented throughout the USA<sup>1</sup> and recently in Scotland to investigate a rapidly growing outbreak<sup>2</sup>
- Little is known about patient and healthcare worker acceptability of the use of this data, particularly where individuals may be identifiable from analyses

### We aimed to identify:

- How phylogenetic data can be used acceptably in the context of HIV PHI
- What safeguards are required
- Negative outcomes that may result from unacceptable use

## METHODS

- Focus groups and in-depth interviews with people living, HIV negative men who have sex with men (MSM) and healthcare staff in Brighton and London, UK, were conducted
- Illustrated explanations of phylogenetic concepts and clinical vignettes describing potential uses of phylogenetic data to guide PHI were presented. These varied from retrospective anonymous use, to use of identifiable data used to directly target 'high risk' groups
- Audio recordings were transcribed verbatim and analysed thematically

## RESULTS

### 1. Acceptability of the use of HIV phylogenetics for public health purposes was determined by the balance between perceived risks and benefits

- Acceptability was highest when data were anonymised, and/or prevention benefits were greatest. Three themes underpinned the discussions:

#### Theme 1. Stigma (risk)

- Stigma was a key barrier to the use of phylogenetics as individuals, or communities could be identified as having, or being high risk for having HIV.
- Some felt people may be reluctant to test for HIV due to this risk

*'This is so highly stigmatised, this subject matter, we are, I have a lot of stigma about this, myself and I fight it, but the stigma out there, you know.'*

MSM, recent diagnosis

#### Theme 2. Blame and prosecution (risk)

- Participants were most concerned about potential blame:
  - Population level: groups being identified as being 'high risk'
  - Individual level: presumption that phylogenetic linkage data may be shared with partners, outside organisations or the police
- The use of public health data for prosecution purposes was a particular concern, with several stating it would be a barrier to testing/engaging with care if these data were police accessible

*'...there are the risks aren't there basically the individual is going to be fingered, pointed at, as um, that's your genetic coding so you did that.'*

MSM, recent diagnosis

#### Theme 3. Public and personal health responsibility (benefit)

- Scenarios became more acceptable as the perceived prevention benefits increased due to a desire to help prevent further infection
- Most participants did not feel phylogenetics would impact on their own testing behaviors or engagement due to a sense of personal health responsibility

*'It would be a little bit embarrassing... but within you, especially for the younger generation you'll be happy to do whatever it takes to eradicate or reduce it. So you'd be happy to do it.'*

Black African woman

### 2. Acceptability was enhanced, even when using identifiable data when specific misunderstandings or concerns were addressed, and protections were in place, including:

#### 1. Data management and security

- Identifiable data only accessible to the direct healthcare team
- Robust security measures, protection from cyber crime
- No use for purposes other than public health, including use for prosecution

*'It all, for me personally it boils down to who has access. If it's restricted to the relevant people having the right access for the right reasons, no problem. It's when it becomes open source, when anybody can gain access to it, or if it gets leaked to the wrong person...'*

#### 2. Transparency and consent

- When using identifiable data, consent was felt necessary as it was thought some individuals may not test for HIV without this assurance
- However when faced with a rapidly growing outbreak scenario, many felt it was not required due to the need for rapid action
- Participants acknowledged the difficulties in consenting patients; the complexities of the concepts, and challenges faced at diagnosis

*'If it was anonymous I wouldn't care so much, you know, it doesn't matter. If it had... detailed information about me attached then yeah, I would want a consent in that situation. I would be really, really annoyed if it wasn't.'*

#### 3. Awareness of limitations of data and improved understanding

- Many automatically presumed we can tell who-infected-who from the data

*'...purely because you're not going to be able to tell which way it was transmitted. If they've transmitted to them, or have they got it transmitted? I don't think that would necessarily put anybody off testing. I wouldn't imagine so.'*

- Understanding the limitations of phylogenetics was reassuring

#### 4. Drawing parallels with standard practice

- Many concerns did not relate to phylogenetics directly, but current standard practice including contact tracing and confidentiality standards

*'They're doing it anyway because if you're going to be having sex and you come to a clinic anywhere in the world, like this, you're being monitored because you've got a piece of paper with your name and everything written on it, it's no different....'*

Table 1. Participant demographics

	Focus groups (participants /group)	Interviews
HIV positive MSM diagnosed ≤ 5 years ago	1 (n=7)	2
HIV positive MSM diagnosed > 5 years ago	1 (n=5)	2
HIV positive black African men	1 (n=6)	3
HIV positive black African women	1 (n=7)	2
HIV negative MSM	1 (n=6)	
Healthcare workers within the field of HIV	1 (n=9)	

## CONCLUSIONS

- Acceptability of the use of phylogenetics to guide PHI is dependent on perceived risks vs. public health benefits
- If considering the use of phylogenetic data that can be linked back to individuals:
  - Evidence to suggest significant public health benefit is required
  - Methods of protecting this data from judicial use need to be identified
  - Strategies for informed consent and information provision require development
  - Access to data needs to be strictly limited, and security measures robust
- Implementing phylogenetics to guide PHI in the UK without addressing these issues potentially risks harm, including disengaging individuals from testing or care

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