

# myHIV Forum – The importance of an online platform for people living with HIV

J. Fielder<sup>1</sup>, M. Rattue<sup>1</sup>, K. Scott-Loach<sup>1</sup>, G. Taylor<sup>2</sup>, S. Kumar<sup>2</sup>, W. Smith<sup>2</sup>, D. Sgorbati<sup>2</sup>

<sup>1</sup>Terrence Higgins Trust, Living Well, London, United Kingdom,

<sup>2</sup>NHS Health Economics Unit, London, United Kingdom.

## Background

How do you analyse and understand eight years of valuable HIV online forum history while preserving the anonymity of the online members?

Terrence Higgins Trust's online platform myHIV forum launched in 2011, during a time where online services were still in their infancy. It was set up because people living with HIV (PLHIV) were experiencing high levels of enacted and internalised stigma around their status and they wanted to share common experiences and support each other.

In 2020, Terrence Higgins Trust moved to a new digital platform and recognised the conversations contained within myHIV were a valuable piece of history on the impact of digital health communities on patient-centred care – a decade-long collection of personal narratives and trends, changes to medical pathways, and diverse experiences that emerged over that time.

We aim to use these insights to inform future client care and enhance the lived experience of PLHIV.

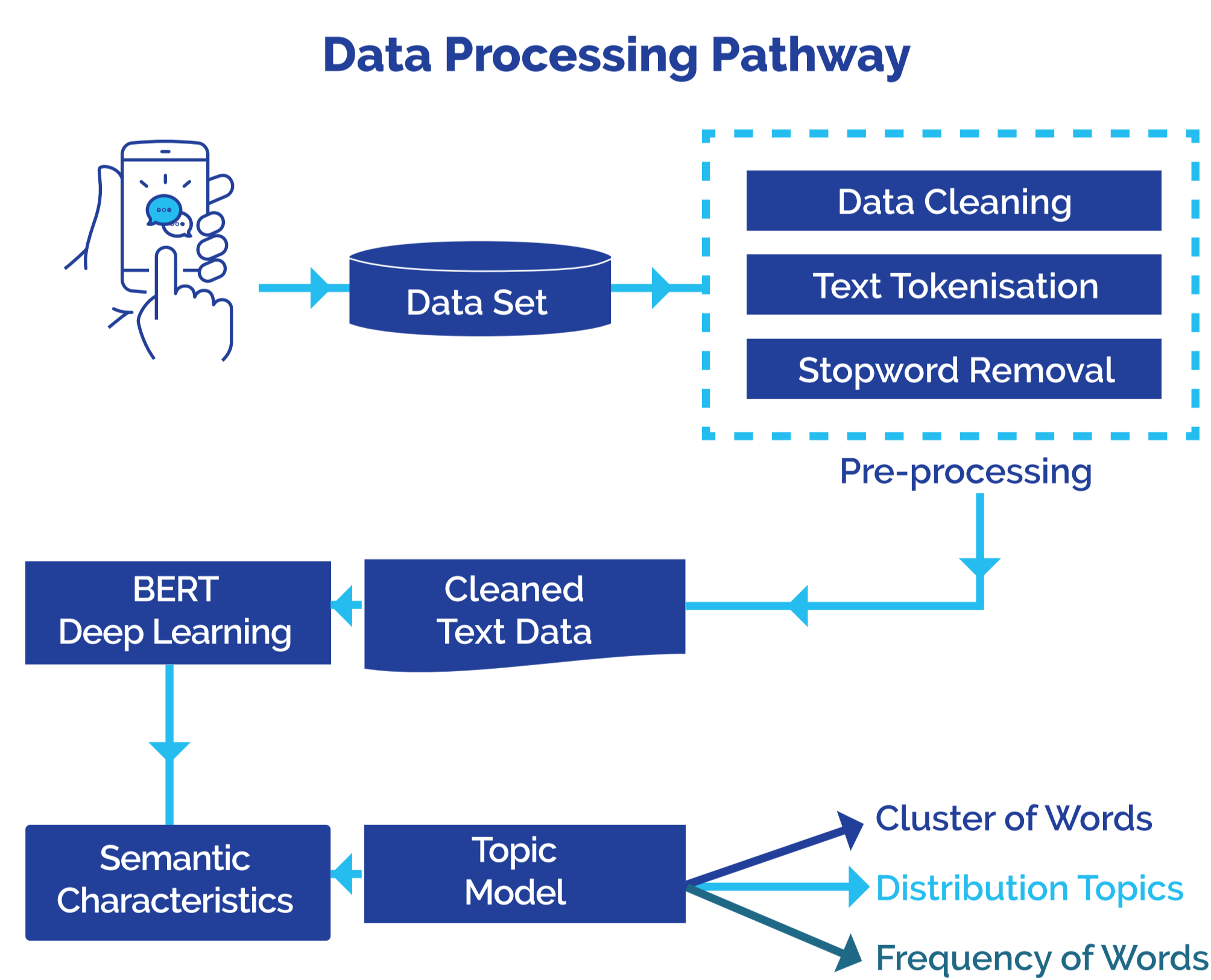
### Outcomes

The project aimed to:

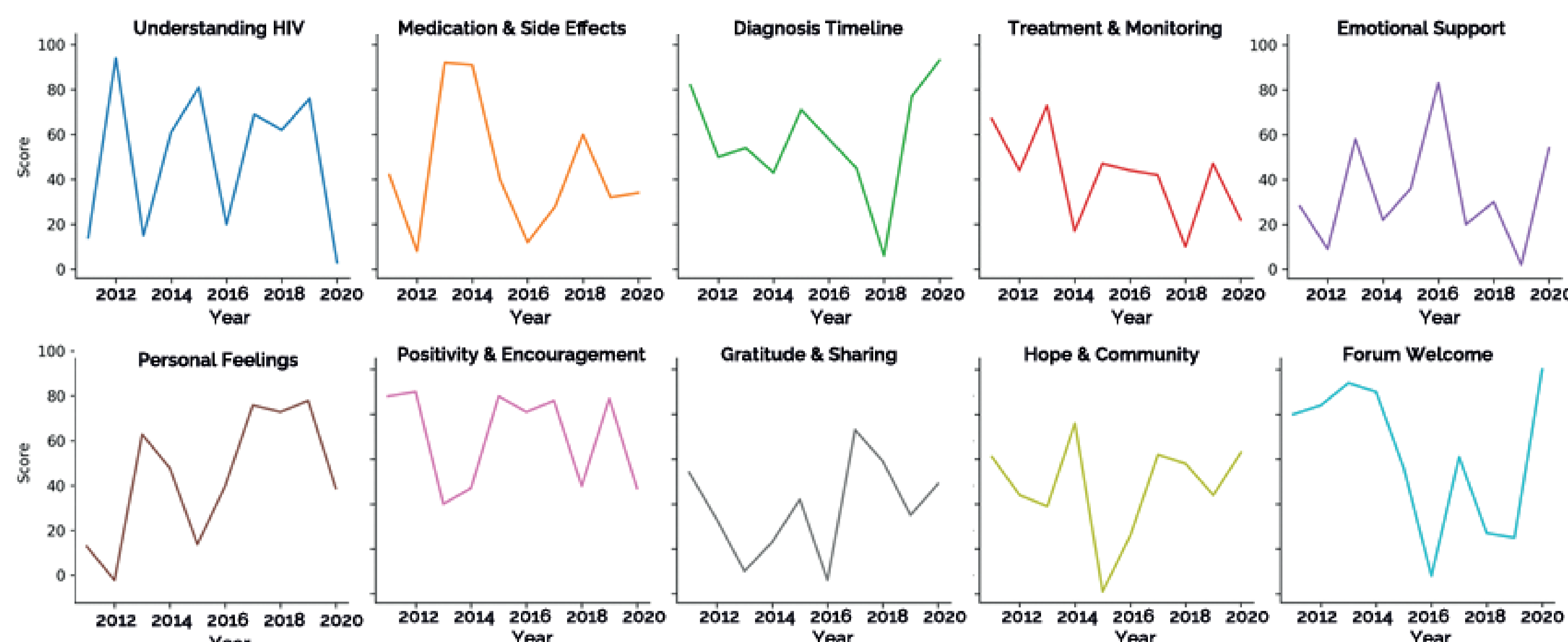
- Understand how the experiences of people living with HIV have changed over time, as treatment protocols evolved and public perception of HIV/AIDS shifted
- Understand the impact of HIV on the lives of people living with HIV in areas ranging from relationships and sexuality to housing, work, and mental health
- Understand changes in HIV care and treatment and in health workers' attitudes towards people living with HIV.

### Who's involved?

The project was shaped by a Steering Group comprised of current forum members and volunteers and also members who were active in myHIV forum and the Health Economics Unit (HEU).



## Prevalence of Topics in the UK 2011-2020



## Methods

We used natural language processing to analyse thousands of posts from the myHIV forum, spanning the eight years it was active. The algorithm broke written content down into smaller segments and pulled out frequently appearing words for topic modelling.

Our analysis stems from a database of **50,821 posts** from February 2011 to November 2020, covering **7,046 topics**.

The forum had **5,067 registered members**.

Our primary data source is **England**.

To ensure the anonymity and confidentiality of forum members, the data was stripped of any identifiers, before being securely moved to an access-restricted NHS server.

We used BERTopic, a Python library, and topic modelling - a statistical NLP technique to unearth the abstract 'topics' within the posts. Our code, which is fully reproducible, is available in Jupyter Notebook.

Using in-depth topic modelling we were able to build a valuable picture of the forum's archive and how discussions changed over time and location, statistically inferring the themes discussed in the text and validating emerging themes with the Steering Group.

Working with Terrence Higgins Trust, we grouped these keywords into 10 most-discussed topics, such as understanding HIV, medication and side effects, and emotional support. For example, the topic medication and side effects included frequently used words such as 'drug', 'regimen' and 'dosage'.

The themes were extracted using a machine learning algorithm so no analyst directly read the already anonymised data.

Approaches to identifying common themes included:

- Clustering by geographic location and time to understand how the journey varied among different people.
- Only IP addresses attached to posts were preserved, to show location related to themes. This was generalised to cities or countries to preserve anonymity.

## Results

*"A treasure trove of real-life experiences and reflections"*

Results revealed the **transformation of discussions over time**, from understanding HIV and emotional support (2011), to medication/treatment (2014), to the emotional journey and resource sharing (2016). By 2018, the emphasis was on testing experiences and emotional support, culminating in 2020 with the high need for emotional help and clinic visit experiences.

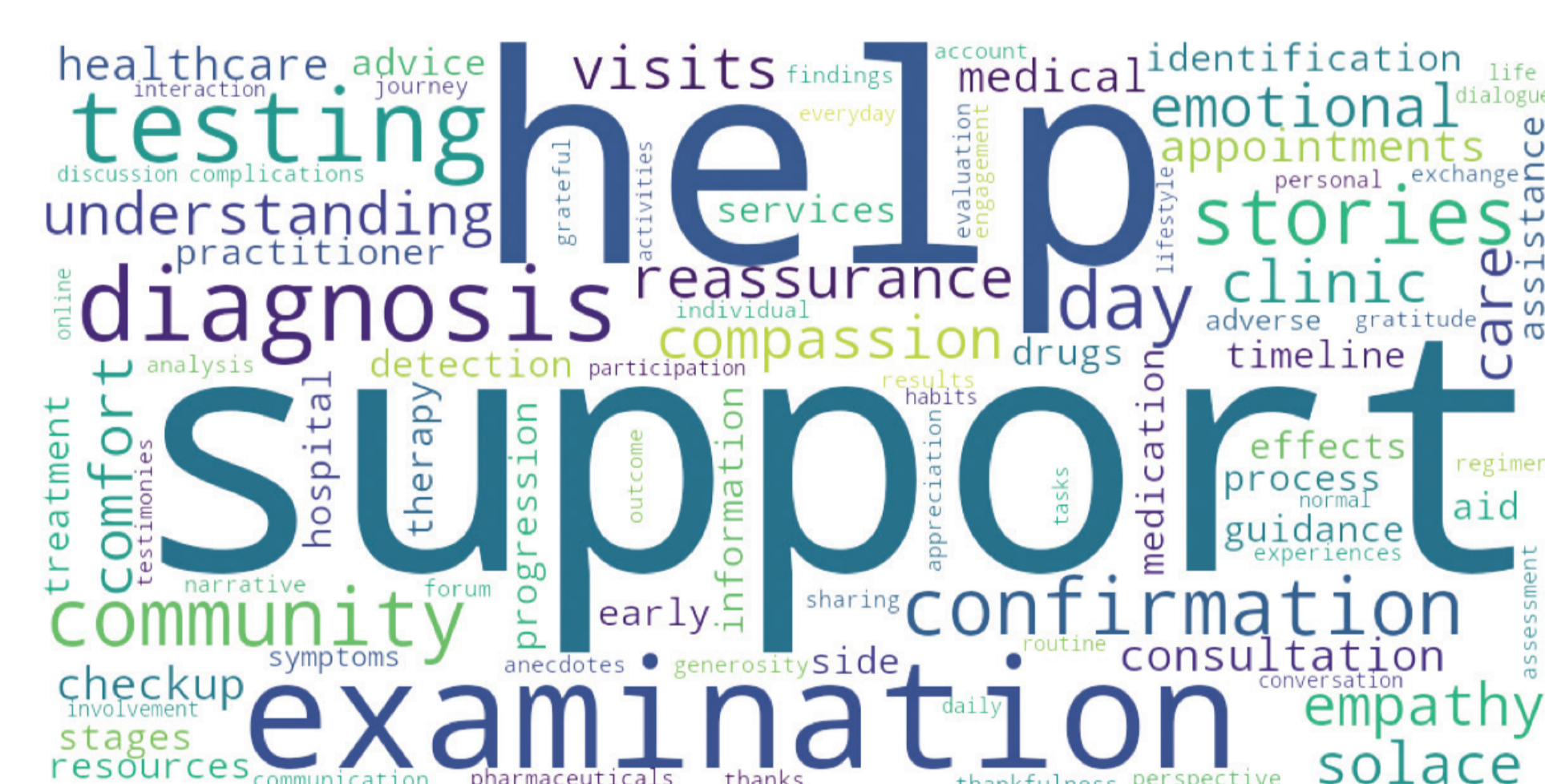
## Conclusions

Our analysis underscored the forum's critical role for PLHIV, particularly in the early days when there was scarce online information. The forum facilitated crucial peer-support and knowledge exchange around treatment aspects. This peer-to-peer platform fostered a positive shift in living with HIV, emphasising the importance of testing and prevention using PrEP from 2011 to 2022. The findings underline the immense benefits of open online platforms for managing health conditions like HIV.

The trust is now exploring how to communicate these findings further and how to use these key learnings to influence future approaches to peer support, self-management and treatment.



Watch our video



Topics across the UK in the year 2020

## Most popular topics per year 2011-2020

Topic 1: Understanding HIV  
Topic 2: Medication & Side Effects  
Topic 3: Diagnosis Timeline  
Topic 4: Treatment & Monitoring  
Topic 5: Emotional Support  
Topic 6: Personal Feelings  
Topic 7: Positivity & Encouragement  
Topic 8: Gratitude & Sharing  
Topic 9: Hope & Community  
Topic 10: Forum Welcome

Topic 1: Support & Discussion  
Topic 2: Treatment Progress  
Topic 3: Daily Routine  
Topic 4: Diagnosis Timeline  
Topic 5: Personal Feelings  
Topic 6: Coping & Adapting  
Topic 7: Gratitude & Advice  
Topic 8: Encouragement & Empathy  
Topic 9: Emotional Support  
Topic 10: Forum Welcome

Topic 1: Treatment Routine  
Topic 2: Support & Information  
Topic 3: Time Since Diagnosis  
Topic 4: Personal Thoughts  
Topic 5: Adjusting & Waiting  
Topic 6: Treatment Success  
Topic 7: Gratitude & Tips  
Topic 8: Progress & Encouragement  
Topic 9: New Diagnosis  
Topic 10: Forum Events

Topic 1: Emotional Journey  
Topic 2: Treatment Options  
Topic 3: Testing & Diagnosis  
Topic 4: Medication & Side Effects  
Topic 5: Progress & Well-being  
Topic 6: Personal Feelings  
Topic 7: Gratitude & Support  
Topic 8: Community Interaction  
Topic 9: Forum Welcome  
Topic 10: Sharing Experiences

Topic 1: Support & Community  
Topic 2: Testing & Results  
Topic 3: Treatment Options  
Topic 4: Personal Feelings  
Topic 5: Past Experiences  
Topic 6: Medication Routine  
Topic 7: Coping & Relationships  
Topic 8: Diagnosis & Adjustment  
Topic 9: Gratitude & Updates  
Topic 10: Personal Strategies

