

Significant Stigma and Barriers to Care are a Reality for People Living with HBV Infection in the United Kingdom – Results of a Mixed Methods Study

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Introduction

Hepatitis B Virus (HBV) infection is a major global health concern, leading the World Health Organization to set targets to eliminate HBV as a public health threat by 2030. Very few countries (including the UK) are on target to meet elimination targets, and a UKHSA report published in 2023 highlights areas in which the UK needs to accelerate progress in order to achieve HBV elimination.

One of the issues hampering elimination efforts is the disjointed and complex care pathway for HBV. The aim of this study was to better define the barriers for HBV care from both the perspective of health care professionals (HCP) and more importantly people living with HBV through a mixed methods approach.

Methods

An online survey of HCPs was carried out using an email invite to all members of the British Viral Hepatitis Group. Reminders were sent twice. The answers to the six questions asked were categorised using the Likert Scale. In addition, HCPs were asked for their top two choices of alternative languages for patient material provision.

The lived personal experiences and perceptions were ascertained through an on-line focus group organised by the British Liver Trust. Open questions were used to explore these with key opinions clustered into themes. Participants were provided with Amazon vouchers as a small token of appreciation for their time.

Results of HCP Survey

67 HCPs responded to the survey. Of the 38 who responded with job roles, there were 13 clinical nurse specialists, 12 hepatologists, 6 pharmacists, 3 infectious disease doctors, 2 virologists and 2 nurses working in liver care. Almost 70% of respondents (see table below) agreed or strongly agreed that HBV diagnosis should be decentralised from secondary care, but there was lack of consensus as to where ongoing clinical provision is best provided. HCPs recognise stigma as a barrier to care and advocate for more research in this space. Cantonese/Mandarin, Urdu and Romanian were by far the most requested languages accounting for accounting for 2/3 of the choices as illustrated in the pie chart below.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
People living with HBV infection encounter many barriers in the current UK continuum of care.	26.87%	35.82%	26.87%	7.46%	2.99%	100%
Stigma is a barrier to engaging people living with HBV infection in care in the UK.	26.87%	41.79%	19.40%	11.94%	0.00%	100%
HBV diagnosis pathways in the UK should be decentralised (moved from secondary/tertiary to primary care/community).	28.36%	41.79%	7.46%	17.91%	4.48%	100%
HBV clinical care in the UK should be decentralised (moved from secondary/tertiary to primary care/community).	14.93%	25.37%	14.93%	31.34%	13.43%	100%
More research is needed into barriers to accessing service provision for people living with HBV infection in the UK.	43.28%	50.75%	2.99%	1.49%	1.49%	100%
E-Health solutions should be explored to increase diagnosis, linkage to care and retention in care for people living with HBV infection in the UK.	41.79%	44.78%	11.94%	0.00%	1.49%	100%

Results of the Online Patient Focus Group

The British Liver Trust was solely responsible for the voluntary recruitment of patients using its standard communication channels. 10 patients living with HBV were interviewed for 2 hours using a Zoom platform by AME, PM and KJ with SW facilitating/chairing. The numbers were capped to ensure adequate opportunities for all participants to contribute to the discussion.

The participants consisted of 5 males and 5 females with 4 born overseas. The age range was 32-73. Participants were asked to briefly talk about their HBV journey but no further clinical details (other than those disclosed by themselves) were ascertained.

A number of themes emerged during the conversation and were explored with further questioning –

1. Despite the fact that all participants had very different routes to diagnosis of HBV, they all agreed that there was a lack or relatable patient information provided to them at the time.
2. Many of the participants had experienced occasions when they had to chase results or felt disempowered to ask questions about their condition during clinical consultations.
3. Lack of awareness and stigmatising behaviour from untrained HCPs was often experienced and was particularly damaging/disheartening.
4. Many participants felt unable to confide their diagnosis to their close family and friends.
5. The development of a HBV specific mobile application was universally supported with the caveat that this was an IT savvy group of individuals.
6. HBV specific peer support roles were welcomed, with several people expressing that they would prefer to speak to someone who has lived experience than someone who's "just read some notes".

Selected Quotes from Patient Focus Group

People experience stigma and many don't feel able to be open about living with hep B

stigma is a huge issue

I've told my family but not all of them have had a test

I was managed in an infectious disease dept for a while which I don't like - people usually think and that they need to stay away from friends (partner - better)

stigma especially an issue around marriage - impacted how I was seen as a potential partner and mother

stigma is an issue for people with HBV

I am concerned about how people would react / treat me if they knew

I've had no issues or bad reactions telling HCPs

I haven't told family and friends (aside from 'my rock')

When I get bloods for Crohns, I ask them to add Hep B tests - they shout it across the room and I don't want that info shared

I told some friends - some ok but others have said things like 'who have you been with?'

I don't feel I can tell anyone beyond my mum and my partner

I'm scared of telling my children, but from what I read how they might find out eg if something happens to me (the mother) (participant's mother)

People would like to be able to talk to someone and like the idea of peer supporters

I wish there had been some kind of counselling available when I was diagnosed - what to do, how to cope, how to tell people

Being able to talk to a normal person who's lived it would have made a huge difference (at Dx or more generally)

like others, think peer support is important (BHO only so much you can do as a peer)

being able to read stories too as well as talking to someone. You maybe wouldn't know how to start the conversation.

Agree talking to someone with lived experience is better than someone with no real connection

going to the support group helped put it into perspective and to accept it so could move forward

peer support is really important

Finding the Trust's support group made a huge difference to me

(from options) I'd prefer to speak to someone with lived experience over someone who's 'just read some notes'

would like to be able to talk to someone

What people would like app to do

credible info that can be updated

info / app should emphasise the positives - screening, vaccination, early treatment

good to have the facts and avoid misinformation

enough info to flag up key issues and signpost issues (plus a contact for personal concerns eg Trust helpline)

digital and offering peer support are important

being able to read stories too as well as talking to someone. You maybe wouldn't know how to start the conversation.

would like to be able to order blood tests through the app and see the results there automatically

idea of the app as a tree and can follow the different branches as needed

would like to have vaccination info for family members - keep track of whether anyone needs booster etc

able to see and monitor data, useful if move elsewhere

I'd like info on how to help myself

Support for an app

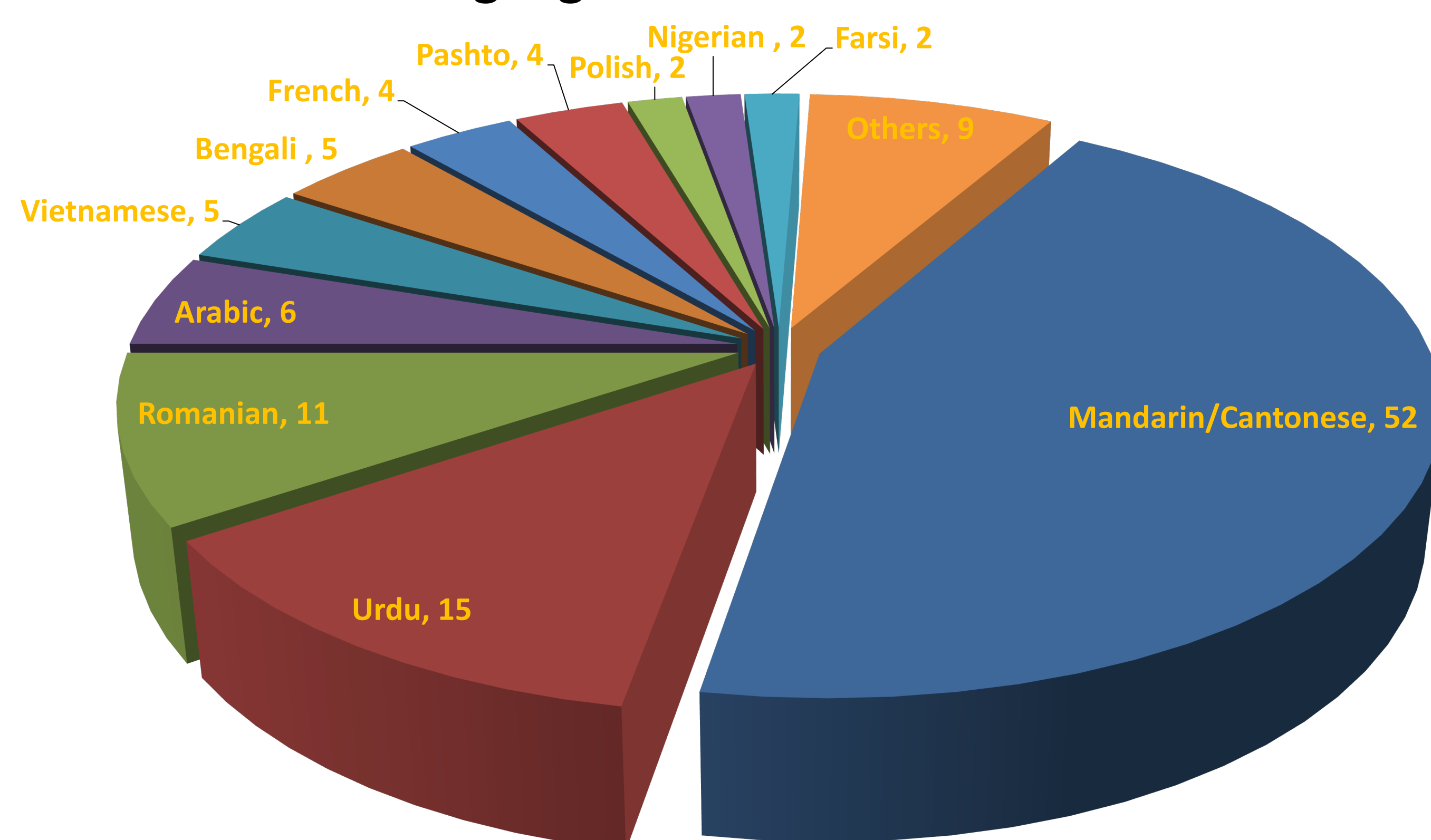
digital connection is the future and many would benefit especially younger people

app is a brilliant idea, I'd have loved that when I was diagnosed

Like the idea of an app, can start discovery journey slowly.

fantastic idea to have an app

HCP Language Choice for Patient Materials



Conclusions

- Both HCPs and patients agree that there are many barriers to effective delivery of care exist for people living with HBV in the UK.
- Stigma in particular from both non-trained HCPs as well as family/friends remains a major issue with many patients reluctant to disclose their diagnosis even to their 'nearest and dearest'.
- Electronic solutions represent a potential avenue for providing linkage to care and educational resources. Peer support is also a crucial avenue that requires further exploration/investment.
- These changes need to be carefully evaluated, however, to ensure current inequalities of access are not exacerbated.

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