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ORIGINAL RESEARCH

Optimising Surveillance in Hepatocellular Carcinoma: Patient-Defined Obstacles and Solutions

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Background and Aims: Six-monthly ultrasound surveillance for hepatocellular carcinoma (HCC) is recommended in patients with cirrhosis. Surveillance enhances early detection and improves survival. Yet, despite clear benefits, uptake remains low. We aim to identify and explore ways to overcome patient-related barriers to HCC surveillance with the aim of producing invitations for surveillance.

Methods: Using the COM-B model of behaviour and a co-design process, we collaborated with patients, liver health charities and advocacy groups, to identify patient-related barriers to attending HCC surveillance. We performed qualitative thematic analysis of coproduction workshops on HCC surveillance to develop information leaflets and surveillance invitations.

Results: Twenty-eight participants attended five workshops. Fear of a serious diagnosis and stigma from healthcare professionals were highlighted as main patient-related barriers to attending surveillance appointments. Co-design was used to develop informative, userfriendly, non-judgemental invitations and information regarding HCC surveillance relevant to populations with cirrhosis.

Conclusion: We identified potential patient barriers to surveillance uptake and developed patient facing material that directly addressed these barriers to be trialled in the clinic. Targeting patient-specific barriers may increase uptake of surveillance and therefore enhance early diagnosis.

Plain language summary: Ultrasound surveillance for hepatocellular carcinoma (HCC) is recommended for those with chronic liver disease, but surveillance uptake remains low. Fear and concern about stigma from healthcare professionals are widespread and act as barriers to surveillance attendance. Through a co-design process, we designed invitations to surveillance alongside informational material, aiming to address the self-reported barriers and motivators to surveillance attendance.

Keywords: hepatocellular carcinoma, surveillance, communication, co-design

Introduction

Hepatocellular carcinoma (HCC) is a growing health concern globally, with a steadily rising incidence, and a prognosis that has remained poor (<20% survival at 5 years) over the last decade.¹ The majority (80–90%) of HCC arise on a background of cirrhosis or chronic liver disease, thus identifying a target "at risk" population for receipt of a surveillance test. Surveillance for HCC involves six-monthly ultrasound, and is recommended by international professional bodies.^{2,3} Six-monthly ultrasound has been demonstrated to improve early cancer detection and survival and is cost-effective.^{4,5} However, the rates of surveillance uptake are less than 25% internationally.⁶ Barriers to HCC surveillance uptake are multifactorial, with patient, healthcare provider and system factors being identified.⁷

Patient-related barriers to surveillance uptake have been identified for various cancers^{8–10} and include income and education level, socioeconomic status and immigrant background (those born outside of the country they currently

reside). The research examining patient-related barriers to HCC surveillance is limited to American and Asian cohorts:^{9,11} they include financial barriers, challenges in scheduling appointments and transportation difficulties.

The UK Health Security Agency reports that many patients with liver disease are from "marginalised groups" living in "unstable accommodation" with limited English language skills.¹² A significant proportion of people who experience homelessness have chronic liver disease: a recent study in the UK found that 50% had alcohol dependence and 39% were hepatitis C positive.¹³ Those experiencing homelessness have a life expectancy of three decades less than the general population. Cancer accounts for one-fifth of deaths in homeless people, and almost one-third of total deaths in the population are considered preventable.¹⁴ The UK Health Security Agency also notes that dependence on alcohol and drugs might result in difficulty attending appointments, which is supported by evidence in the US that patients with current alcohol misuse had lower attendance at surveillance than those who did not drink alcohol.⁷ Additional barriers faced by marginalised communities are low literacy levels, lack of understanding about underlying disease, difficulty in getting to the hospital and fear of stigma about their lifestyle.¹⁵

Whilst patient related barriers are particularly important in those experiencing socioeconomic deprivation, substance misuse and competing priorities,^{16,17} there is low surveillance uptake across all demographics.¹⁶ This suggests that other extrinsic factors, including healthcare-system barriers (for example, lack of recall systems for surveillance) and physician barriers (such as lack of information provided about cancer risk), may be influencing surveillance uptake. A UK survey of gastroenterologists and hepatologists found that 29% of hospitals did not provide written or verbal information about HCC surveillance to patients.¹⁸ Thus, it is of paramount importance to develop informative, relevant and user-friendly HCC surveillance information and invitations designed to empower patients¹⁹ and encourage surveillance attendance.

The traditional approach to scientific research is one in which there is a power imbalance between researchers and those whom the research concerns.²⁰ Patient priorities are infrequently considered, resulting in the generation of research questions which may not be relevant to patients' lives or wellbeing.²¹ Co-design, or co-production of research, embraces shared responsibility and ownership of research, resulting in "the meaningful involvement of end-users in research".²² Practically, this can include utilising questionnaires, focus groups and interviews with the aim of producing high-quality research with real-world impact for patients.²³ Co-design has been shown to improve patients' knowledge, skills and confidence in managing their conditions.²⁴ Experience-based co-design (EBCD) has been used previously in lung, breast and colon cancer,²⁵ with the partnership between patients, researchers and clinicians resulting in production of information booklets, consultation letters and methods of breaking bad news.²⁶ Co-design has been valuable in highlighting patient perspectives²⁷ and identifying specific "touchpoints" which shape patient experience, including side effects of medications or post-operative recovery.²⁸ This approach has not been used in HCC and through engagement with healthcare users may improve attendance to appointments.

Our aim was to co-design HCC surveillance information materials to address the low uptake of surveillance. We sought to explore the barriers faced by patients in attending HCC surveillance, identifying common themes and collaborating with patients to address these. We aimed to form a collaboration with patients, advocacy groups and behavioural specialists to develop informative, relevant and user-friendly invitations to encourage surveillance attendance.

Materials and Methods

We collaborated with patient advocacy groups (The British Liver Trust, The Hepatitis C Trust and Groundswell), patients and a behavioural specialist team (Claremont Communications) to identify patient-related barriers to HCC surveillance attendance and co-design surveillance invitations encouraging attendance.

The patient advocacy groups had expertise in supporting populations that are over-represented in HCC (those experiencing homelessness, patients with hepatitis C and patients with chronic liver disease):

- 1. Groundswell, an organisation aiming to create solutions to end homelessness, designed by those with lived experience.
- 2. The Hepatitis C trust, a patient-led charity aiming to educate and raise awareness about hepatitis C and support those living with hepatitis C
- 3. The British Liver Trust, the UK's largest liver charity, which aims to raise awareness and provide support for liver disease and liver cancer.

Patients were identified and approached through the charities' own outreach teams. Five co-production workshops were held: three held face-to-face in London, and two held online. These were attended by twenty-three participants with lived experience of liver disease and five charity representatives. All workshop participants were adults aged 18–70; both men and women were represented (59% male) and there was diversity of ethnic groups (representation from white, black and mixed ethnicities). Participants had varying aetiologies of liver disease (viral hepatitis, alcohol-related, metabolic, autoimmune), literacy and socio-economic background. There was representation from across the spectrum of experience and knowledge about liver disease: some participants were recently diagnosed, and had no previous engagement with healthcare services, while others had decades of experience as patient representatives for liver disease. Ten participants had experience of homelessness and several members had lived experience of substance misuse. Participants were treated as peers and efforts were made to ensure all members contributed equally. Demographic characteristics of participants are outlined in Table 1.

Participants were asked to share their experience of HCC surveillance, the decision to attend or not attend appointments, including motivational factors and barriers and their opinions of invitations to surveillance. Workshops were asked the same broad questions, including "What might make you more likely to attend an appointment?" and "What might put you off [from attending] a liver cancer surveillance?", with further exploration of issues raised by each group. Participants completed activities within the workshops, discussing and designing a surveillance invitation aiming to encourage attendance. Invitations were developed using an iterative process with participants.

The capability, opportunity, motivation, behaviour (COM-B) model²⁹ was used to map potential factors that might influence individuals' participation in a surveillance programme. The COM-B model postulates that behaviour is influenced by the interaction between capability, opportunity and motivation and therefore highlights potential barriers to be addressed. We explored potential reasons for non- or under-attendance at surveillance appointments utilising this framework. Workshops were recorded with participant informed consent, transcribed and thematic analysis performed.

The specific work detailed in the manuscript is considered PPI work (patient and public involvement) and as such does not require approval from an ethics committee. We obtained written informed consent from all participants, including for publication of anonymised responses, and our wider research into barriers to HCC surveillance has been approved under the name PRECISION (IRAS number: 198951) by the Sheffield Research Ethics Committee.

Results

Patient Barriers to Surveillance Attendance

Participant-reported barriers to surveillance were grouped into themes, utilising the COM-B model. These are detailed in Figure 1.

Capability

- a) *Not understanding the surveillance invitation letter*. Participants and charity workers emphasised that medical correspondence is consistently difficult for them to understand, due to use of medical jargon, patients' low literacy skills or a limited understanding of English.
- b) *Inability to receive post*. This was a barrier not only to rough sleepers, but any participants who did not have a fixed address, including those temporarily staying with family members.

	British Liver Trust (n=11)	Hepatitis C Trust (n=10)	Groundswell (n=7)
Gender	12.5% Male	87.5% Male	73% Male
Ethnicity	100% White	73% White	87.5% White
Aetiology*	Metabolic liver disease, autoimmune, alcohol-related liver disease	Viral hepatitis	Viral hepatitis and alcohol-related liver disease

Table I Demographic Characteristics of Workshop Parti
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Notes: *Exact numbers for each aetiology not available as not all participants felt comfortable to share aetiology of liver disease.

Type of Barrier	Barrier	Groundswell (n=7)	Hepatitis C Trust (n=10)	British Liver Trust (n=11)
	Not understanding the letter (literacy, medical terms)	Х	Х	
Capability	Cannot receive post (moving or no address)	X	Х	
	Cannot commit to appointments ("chaotic lifestyle")	Х	Х	Х
Onnortunity	GP or healthcare professional never made them aware		Х	Х
Opportunity	Transport or financial issues with travel	Х	Х	
	It won't happen to me		х	
	I'm scared	Х	Х	Х
Motivation	I'm going to die anyway	Х		
	I've had a bad experience (stigma, poor NHS treatment)	Х	х	Х
	I don't want my current medications / drugs taken away	х		

X highlights which barrier was identified by each workshop group: for example, the "cannot receive

post" barrier was identified by participants in the Groundswell and Hepatitis C Trust workshops.

Figure I Barriers to surveillance attendance identified through workshops.

c) Unable to commit to appointments due to lifestyle. Participants commented on difficulty making plans when using alcohol or recreational drugs, while some explained "you avoid the doctor when you have a chaotic lifestyle".

Opportunity

- a) *Lack of awareness about their appointment, or significance of the appointment.* Participants felt that healthcare professionals avoided mentioning cancer altogether and "you are not told what they are looking for" in surveillance ultrasounds: this can lead patients to de-prioritise the appointment.
- b) *Challenges with transport*, especially if the hospital is far away. Some participants were unable to travel further than a few miles for an appointment; others are unable to use public transport due to lack of confidence.

Motivation

- a) *Denial* about liver disease and its consequences was frequent, sometimes leading to disengagement with healthcare ("I do not need to hear this")
- b) Fear was frequently cited by participants in all groups: "I would not want to find out if it was bad news".
- c) *Pessimism and fatalism* was highlighted in groups experiencing homeless. Common health beliefs amongst this group included "I am going to die anyway", "I thought I was too far gone" and "what's the point in stopping now".
- d) Concern about stigma regarding underlying condition. All groups, irrespective of aetiology of liver disease, raised this as a significant barrier, with one participant describing stigma as "one of the biggest setbacks" in attending surveillance. Participants shared anecdotes about comments alluding to alcohol and drug use made by healthcare professionals, with some reporting that these had long-lasting impacts on their relationship with healthcare. Patients with no previous substance misuse feared being mislabelled as having alcohol-related liver disease or being intravenous drug users.
- e) *Apprehensive about current medication being taken away.* This specific concern was discussed at length by groups who experienced substance misuse: for these individuals, there is an additional concern that medication such as methadone will be denied at a hospital visit with lasting effects in the community setting, Participants described being "punished" by their local pharmacy team following hospital admissions where methadone was not given; this translated into reluctance to attend any further hospital appointments.

How Should We Communicate with Our Audiences?

We then explored methods in which users would like to receive information regarding surveillance appointments. Workshops held with the British Liver Trust and Hepatitis C Trust revealed that participants wanted surveillance invitations posted on NHS headed paper in white envelopes. Brown envelopes were associated with communications from the government, specifically the Department for Work and Pensions, and users described fear or disappointment on receiving brown envelopes. Digital reminders in the run-up to the appointment were considered helpful.

Invitation Development (Figure 2)

Depending on aetiology of disease and personal preference, patients place trust in different members of the multidisciplinary team. Workshops revealed that certain patient groups (those with established non-viral cirrhosis) placed their



Recipient's Name Address 1 Address 2 Address 3 Address 4 Postcode

Private and confidential

Dear [Firstname lastname]

Your liver health check

Your healthcare professional has enrolled you onto a screening programme to monitor your liver health. A liver health check can identify liver cancer before any symptoms appear. This makes treatment simpler and more successful, for those who need it.

What happens during the appointment?

A liver health check involves an external ultrasound scan of the liver. This is a quick and painless test that takes around 15-30 minutes.

"I send my patients for liver screening every six months. Liver scarring can be caused by a number of factors, but the most important thing is that any complications are caught early." -- Dr Vinod Sharma, GP

What to do before your scan

You will need to **stop eating for six hours before the scan**. Please let us know if that will be a problem for any reason (for example, if you have diabetes). You can continue to drink water and take any medications as normal.

What happens afterwards?

If the ultrasound highlights any concerns, then we will arrange for you to have a follow up appointment to discuss your results.

We have booked the following appointment for you at Hammersmith Hospital for your liver health check:

Xpm on XXX May 2022

Please call 020 XXXX XXXX if you need to change this appointment.

How do I get there?

XXX Hospital XXX Address 1 XXX Address 2 XXX Address 3

For information about how to reach the hospital, please search "Find XXX Hospital" or call 020 XXXX XXXX.

You can find further information about liver screening at <u>tinyurl.com/liverscreening</u> or by contacting your healthcare professional.

This information was developed with support from the British Liver Trust and The Hepatitis C Trust

Figure 2 Invitation to HCC surveillance, co-designed with patients, advocacy groups and behavioural specialists.

trust almost exclusively in their hepatologist, whereas those with hepatitis preferred their GP or a clinical nurse specialist. Indeed, many participants were unaware of the term "hepatologist". Therefore, the term "healthcare professional" was used in our invitation. Additionally, the British Liver Trust and Hepatitis C Trust were named in the invitations to foster trust and aid authenticity; a link to a website was included for further invitation.

Use of plain English and avoidance of medical jargon (*liver scarring* rather than *cirrhosis, liver health check* rather than *surveillance*) was used as patients with liver disease are more likely to have lower literacy levels and speak English as a second language. Our workshops also highlighted that those experiencing homelessness were particularly distrustful of medical jargon.

Concerns about stigma were cited as motivational barriers to surveillance attendance; to address this, nonjudgemental language was used (*liver scarring can be caused by a number of factors*). Emphasis was placed on a *quick and painless* test to alleviate fear and encourage uptake.

Participants specifically requested inclusion of the word "cancer" in the invitations: despite fear of serious illness, patients valued honesty and felt that providing clarity on indications for surveillance would encourage attendance.

Need for Explanatory Postcard (Figure 3)

Participants specifically requested the addition of an explanatory postcard to be added to the invitation. They wanted a brief explanation and illustration of the procedure to alleviate fear and promote understanding of the surveillance process even amongst those with minimal literacy levels. The "zoom in" aspect of the illustration was developed to emphasise that the scan is external. Concerns about pain and length of procedure were addressed specifically with description of a "quick and painless" scan lasting "15–30 minutes". A green background was suggested as our groups associated this colour with health and wellbeing.

People Experiencing Homelessness Require a Different Approach

The workshops held with Groundswell and those experiencing homelessness made apparent that a tailor-made approach is required to target surveillance in populations experiencing homelessness. Specific challenges that were highlighted included social isolation resulting in difficulty accessing information and appointments, and mistrust of government institutions including the NHS. However, participants placed high levels of trust in their support workers, who often help them navigate the healthcare system. This group suggested that a trusted individual, usually a support worker, would be key to surveillance attendance: they highlighted that support workers usually inform and remind patients about their appointments, encourage attendance and physically accompany them to the hospital, helping them navigate public transport.



Figure 3 Explanatory postcard to accompany invitation letter.

Discussion

HCC surveillance in target populations (patients with cirrhosis and high-risk individuals with HBV and HCV) results in early diagnosis, early receipt of curative therapy and improves survival.^{4,5} However, under-utilisation of surveillance is almost universal,⁶ and understanding patient barriers will improve uptake.⁷ Screening programmes for bowel and cervical cancer have been successful^{30,31} in engaging patient and public involvement (PPI) as well as aspects of co-design,³² To our knowledge, this is the first co-design process for HCC surveillance, a process that investigates and addresses patient-related barriers through creation of information and an invitation with a view to implementation in real-world practice. This is of key significance as it is known that HCC disproportionately affects marginalised communities and therefore working alongside these groups is especially important to ensure engagement.

Collaborating with a wide range of patient groups, revealed common barriers to attending surveillance. The most common being were fear of diagnosis and apprehension about facing stigma from healthcare professionals. Additionally, patients also cited lack of awareness and understanding about their condition and associated cancer risk factors. Working together, we developed invitations to HCC surveillance, which aimed to address these barriers and encourage attendance.

In addition to this work being novel in the field of HCC surveillance, our study has several strengths. Firstly, the iterative design enabled optimisation of the invitations following review by end-users and patients with HCC. Moreover, our collaboration with a behavioural communications team enabled us to draw upon their expertise of in producing communications for cancer surveillance in low socio-economic groups. This helped in producing a final product aimed at reducing health inequalities.

In addition, we observed that a very different approach is needed for those experiencing homelessness as they may not have access to mail. In this group, HCC surveillance may have to take a tailored approach via support workers or require mobile surveillance units near day centres. The "Find and Treat" project is an example of successful co-design working to improve health outcomes in those experiencing homelessness.³³ Researchers, clinicians and those with lived experience of homelessness work in partnership to manage tuberculosis in the community. Mobile X-ray vans screen for tuberculosis in thousands of people without stable accommodation enabling early diagnosis. A similar method with mobile vans has been used for COVID vaccinations in this population.³⁴ Based on our workshop findings and the success of the Find and Treat programme, we recommend graphical posters in day centres to alert case workers and those experiencing homelessness about the arrival of a mobile surveillance unit to the local area. This surveillance unit can then be stationed outside of day centres. It is likely that further support of case workers would be required to optimise surveillance uptake.

Further work will involve analysis of surveillance uptake following dissemination of these invitations and may explore additional interventions including patient navigators, which have been shown to significantly increase surveillance uptake in the US.³⁵ For the surveillance programme to be optimised physician and healthcare system barriers also need to be addressed.³⁶ Lack of knowledge about HCC and cancer risk was a patient-reported barrier to surveillance attendance: this is a significant and novel finding which highlights the necessity of future work exploring physician attitudes towards discussing cancer.

There are some limitations to our study. We were not able to have representation from patients with every aetiology of liver disease nor ethnic group. This may result in the development of material that does not meet these groups' specific requirements and should be addressed in future work.

In summary, we used an iterative, collaborative approach engaging end users to identify key barriers faced by patients in attending surveillance and developed an invitation to HCC surveillance aimed at increasing patient participation. This will inform further work in eliminating barriers to access for surveillance.

Data Sharing Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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