Acceptance of social media recruitment for clinical studies among Hepatitis B patients in Germany: A mixed methods study

Theresa Willem, Bettina Zimmermann, Nina Matthes, Michael Rost, Alena Buyx

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Theresa Willem[1, 2, 3*]; Bettina Zimmermann[1, 4, 2*] PhD; Nina Matthes[1]; Michael Rost[5] PhD; Alena Buyx[1] Prof Dr Med

[1]Institute of History and Ethics in Medicine TUM School of Medicine and Health Technical University of Munich Munich DE
[2]Institute of Molecular Immunology Klinikum Rechts der Isar Technical University of Munich Munich DE
[3]Department of Science, Technology and Society (STS) School of Social Sciences and Technology Technical University of Munich Munich DE
[4]Institute of Philosophy Multidisciplinary Center for Infectious Diseases University of Bern Bern CH
[5]Institute for Biomedical Ethics University of Basel Basel CH
[*]these authors contributed equally

Corresponding Author:
Bettina Zimmermann PhD
Institute of History and Ethics in Medicine
TUM School of Medicine and Health
Technical University of Munich
Ismaninger Str. 22
Munich
DE

Abstract

Background: Social media platforms are increasingly used to recruit patients for clinical studies. Yet, patients' attitudes regarding social media recruitment are underexplored.

Objective: This mixed-methods study assesses predictors of the acceptance of social media recruitment among Hepatitis B patients, a patient population that is considered particularly vulnerable in this context.

Methods: Employing a mixed-methods approach, the hypotheses for our survey were developed based on a qualitative interview study with six Hepatitis B patients and 30 multidisciplinary experts. For the paper-based cross-sectional survey, we recruited participants from three clinical centres in Germany. Adult patients capable of judgement with a Hepatitis B diagnosis who understand German and visited one of the three study centres during the data collection period were eligible to participate. Data analysis was conducted in SPSS 28, including descriptive statistics and regression analysis.

Results: Based on the results of the qualitative interview analysis, we hypothesized that six factors were associated with acceptance of social media recruitment: Using social media in the context of Hepatitis B (H1), digital literacy (H2), interest in clinical studies (H3), trust in non-medical (H4a) and medical information sources (H4b), perceiving the Hepatitis B diagnosis as a secret (H5a), attitudes towards data privacy in the social media context (H5b), and perceived stigma (H6). Regression analysis revealed that the higher the social media use for Hepatitis B (H1), the higher the interest in clinical studies (H3), the more trust in non-medical information sources (H4a), and the less secrecy around a Hepatitis B diagnosis (H5a), the higher the acceptance of social media as a recruitment tool for clinical Hepatitis B studies.

Conclusions: This mixed-methods study provides the first quantitative insights into social media acceptance for clinical study recruitment among Hepatitis B patients. The study was limited to the German setting and Hepatitis B patients but sets out to be a reference point for future studies assessing the attitudes towards and acceptance of social media recruitment for clinical studies. Such empirical inquiries can facilitate the work of researchers designing clinical studies as well as ethics review boards in balancing the risks and benefits of social media recruitment in a context-specific manner.

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Authors: Theresa Willem[1,2,3+], Bettina Zimmermann[1,2,4+], Nina Matthes[2], Michael Rost[5], Alena Buyx[2]

[1] Klinikum Rechts der Isar, Technical University of Munich, Germany; TUM School of Medicine, Institute for Molecular Immunology, Munich, Germany

[2] Institute of History and Ethics in Medicine, TUM School of Medicine, Technical University of Munich, Munich, Germany

[3] Technical University of Munich, Germany; School of Social Sciences and Technology, Department of Science, Technology and Society (STS), Munich, Germany

[4] Institute of Philosophy & Multidisciplinary Center for Infectious Diseases, University of Bern, Bern, Switzerland

[5] Institute for Biomedical Ethics, University of Basel, Basel, Switzerland

[+] These authors contributed equally to the manuscript and share first authorship.

Corresponding author

Dr. phil. Bettina Zimmermann

Institute of History and Ethics in Medicine, TUM School of Medicine, Technical University of Munich, Munich, Germany

Ismaninger Str. 22, 81675 Munich, Germany

+49 89 4140 4041

bettina.zimmermann@tum.de

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Keywords

Facebook; Twitter; social media; clinical trial; enrolment; health technology acceptance; ethics; infectious diseases; privacy; data protection; stigma; discrimination

1 Introduction

Recruiting clinical study participants through social media has the potential to increase the recruitment accrual in a cost-effective way [1]. This way of recruitment is increasingly used (often in parallel to other recruitment strategies), even though it can be resource-intensive and social media recruitment alone may be of limited representativeness [2]. Recruiting patients via social media comes with ethical issues, particularly for clinical studies. Because social media recruitment includes reaching potential research participants outside a clinical setting and in a public online space without direct personal contact, risks related to social stigma, privacy infringement, loss of trust, and psychological harm have been discussed [3]. To mitigate some of these risks, investigator transparency and explicit consent when recruiting from the network of others was suggested [4]. Yet, because the activities of social media platforms are primarily unregulated and partly belong to large global tech companies, activities conducted on social media, including study recruitment, can never be fully controlled by researchers or institutions. Remaining privacy-infringing risks include hidden data collection and profiling, particularly problematic for patients carrying vulnerable characteristics [5].

There is robust empirical evidence that Hepatitis B patients can be subject to social stigma [6-10]. Therefore, the risk of public exposure to Hepatitis B diagnosis on social media renders them – and patients with other stigmatized traits and conditions – particularly vulnerable in the context of social media recruitment [3]. Yet, social media recruitment can also be beneficial for including patient populations who otherwise would be disregarded for clinical studies [11-13]. For example, in Europe, Hepatitis B is particularly prevalent in certain immigrant populations, which are at risk of being neglected for clinical studies due to language barriers and lack of healthcare access.

The effectiveness of these recruitment strategies hinges on an essential factor: technology acceptance. To date, however, the attitudes of patients regarding social media recruitment are underexplored. Addressing this gap, this mixed-methods study assesses factors predicting the acceptance of social media recruitment among Hepatitis B patients. Based on qualitative individual interviews with six Hepatitis B patients and 30 multidisciplinary experts and a literature review we hypothesized that general social media usage (H1), social media literacy (H2), interest in clinical studies (H3), trust (H4), privacy needs (H5), and perceived stigma (H6) are associated with acceptance of social media recruitment.

2 Methods

2.1 Study design

This study is part of the EU-funded international research consortium “TherVacB – A Therapeutic Vaccine to Cure Hepatitis B”, work package 6 (ethical, legal, and social aspects of social media recruitment). Employing a mixed-methods design, we first conducted an explorative qualitative multi-stakeholder interview study assessing the ethical, legal, social, and practical implications of social media recruitment for clinical studies [2]. The hypotheses investigated in this paper are based on these interviews and a conceptual literature review mapping the ethical implications of social media recruitment [3]. The reporting of this study follows the STROBE guidelines [14].

2.2 Participants, procedure, and ethics approval

Applying venue-based recruitment [15], adult, German-speaking patients diagnosed with acute or chronic viral Hepatitis B were recruited in three large university hospitals in Germany. The clinical staff was instructed to hand every eligible patient in the study period the study information leaflet, explaining the implications of the study to them, and to invite them to fill out the questionnaire. At the beginning of the questionnaire, participants were asked to confirm having read and understood the study information and to consent to the study participation by checking a consent box (see supplementary material). To limit recruitment bias, study nurses were asked to avoid self-selected restrictions in recruitment. Completed questionnaires were collected in the recruiting hospital or sent to the authors via mail. Based on preliminary statistical power analysis and pragmatic considerations of available study participants, we aimed for 200 responses in a recruitment period of seven months. Due to administrative constraints, including the COVID-19 pandemic, the overall recruitment period was prolonged by five months (total recruitment period 12 months, 04/06/2022-31/05/2023) and the recruitment period varied among the recruiting clinics (see Table S2). Overall, 22,0% of estimated eligible incoming patients returned the questionnaire and 72,6% of distributed questionnaires were returned. The ethics committees from the Technical University of Munich (12/22-S-NP), Hannover Medical School (10368_BO_K_2022), and University Clinic Leipzig (189/22-lk) approved the study.

2.3 Survey construction

The dependent variable (Acceptance of Social Media Recruitment) was constructed based on the Technology Acceptance Model [16,17], involving the dimensions of perceived usefulness, perceived ease of use, intentions, and problem awareness, and proved good internal consistency (α = .863). Possible predictors for social media recruitment acceptance were identified based on the above-mentioned hypotheses and operationalized by, if possible, existing validated questionnaires. For three of the nine independent variables we used existing validated questionnaires which were found to be of excellent reliability: the Social Media Literacy Scale (14 items, α = .947) [18], the Berger HIV stigma scale for use among patients with hepatitis C virus (6 items, α = .931) [19], and the Privacy Attitude Questionnaire [20]. For the latter, we included a shortened version that covered the dimensions developed in the Privacy Attitude Questionnaire but targeted it towards the Hepatitis B context. From these dimensions, two subscales were created: secrecy of Hepatitis B diagnosis (2 items, α = .623) and data privacy needs regarding Hepatitis B diagnosis (2 items, α = .587).

For the remaining variables, no validated tools existed. Hence, we developed new scales for each variable of interest. As indicated by internal consistency, these were of moderate, good, or excellent reliability: general social media use (8 items, α = .676), Hepatitis B-related social media use (6 items, α = .906), interest in clinical studies (2 items, α = .895), and trust in information sources regarding Hepatitis B (11 items, α = .905; two sub-scales were created: trust in medical information sources – 4 items, α = .784, trust in non-medical information sources, i.e., traditional media, social media, other patients, poster ads, etc. – 7 items, α = .881). In addition to these adapted and self-developed scales, we included four demographic variables in the regression model (age, gender, education, and mother tongue as an indicator of migration background). A preliminary version of the questionnaire was discussed with three experts from the fields of infectiology and bioethics and then adapted and shortened based on their comments. We then performed cognitive pretesting [21] with six Hepatitis B patients, leading to minor changes. The final questionnaire is provided as a supplementary file.

2.4 Statistical analysis

Using SPSS 28.0, we (1) performed descriptive analyses; (2) determined independent factors associated with participants' acceptance of social media as a recruitment tool for clinical Hepatitis B studies through multiple linear regression analysis; and (3) performed additional exploratory bivariate analyses of Hepatitis B related stigma (i.e., correlation, independent t-test). The statistical significance level was set at $p < .05$. For multiple linear regression analysis, assumption checks were performed before the interpretation of the model (see appendix). For the scale measuring the frequency of social media use, missing values were replaced by "0" (i.e. "never"), assuming that participants did not tick a box, since they did not know the respective social media platform.

For the linear regression analysis, theoretical considerations and hypotheses derived from our previous qualitative study determined predictor selection. In addition, the sample-size/predictor ratio a priori determines variable selection for regression modelling. According to Harrell, a fitted regression model is likely to be reliable when p < m/10 or p < m/20 (average requirement: p < m/15), where p is the number of predictors and m is the sample size (Harrell, 2015). Applying this requirement to our sample size (N=195) and having missing data (80.6% of variables, 28.7% of cases, 3.7% of values), we preliminarily limited the number of included predictors to 11. The following 11 predictors were included in the regression model: general social media usage, social media literacy, Hepatitis B related social media use, interest in clinical studies, trust in medical information sources regarding Hepatitis B (dichotomized to meet assumption of linearity), trust in non-medical information sources regarding Hepatitis B, secrecy of Hepatitis B (dichotomized to meet assumption of linearity), data privacy needs regarding Hepatitis B (dichotomized to meet assumption of linearity), perceived stigma, age, and education.

3 Results

3.1 Deriving hypotheses

After conducting an in-depth literature review on the ethical and social challenges surrounding social media recruitment for clinical studies [3] we developed two semi-structured interview guides, one targeted at Hepatitis B patients, and the other one targeted at multidisciplinary experts. Based on interviews with six patients that were triangulated with findings from 30 interviews with experts, we qualitatively assessed what factors could be associated with the acceptance of social media recruitment for clinical Hepatitis B studies. Based on these findings, we derived hypotheses to be tested quantitatively in a survey among Hepatitis B patients in Germany (Table 1).

Table 1: Hypotheses derived from qualitative interviews regarding factors potentially associated with the acceptance of social media recruitment for clinical studies among Hepatitis B patients.

H1	The more patients use social media for Hepatitis B, the higher their acceptance of using social media as a recruitment tool for clinical Hepatitis B studies.
H2	Digital literacy is associated with social media acceptance.
H3	The higher the general interest in clinical study participation, the higher the acceptance of social media recruitment for clinical studies.
H4	The more patients trust information sources for Hepatitis B, the higher their acceptance of social media recruitment.
H5	The more patients value privacy, the lower their acceptance of using social media as a recruitment tool for clinical Hepatitis B studies.
H6	The higher the perceived stigma of Hepatitis B patients, the lower their acceptance of social media as a recruitment tool for clinical studies.

3.1.1 Intensity of using social media in the context of Hepatitis B

Most of the patients we talked with were rejecting the idea of being recruited for a clinical Hepatitis B study via social media. However, the more active their own part in being recruited would be the more accepting attitudes patients described. For example, patients who described using social media as a tool for informing themselves about potential clinical studies related to their disease were less opposed to being recruited via the same channel. One patient included search engines in their definition of social media and mentioned:

> "You can also advertise on Google. That is quasi/ I think it's better if I [as a patient] search for a study. For example, I search for a study related to psoriasis and enter that term in Google – when the advertisement for a psoriasis study is then made so that it shows up as the first suggestion, [...] I think that's better because in these instances I'm already searching, so I take the first step, I search for the study. And then the study, or the advertisement must be done in such a way that I can find it. So, I take

> the first step and then I land on the study." (patient 3)

Similarly, patients who joined shared interest groups, such as patient groups on Facebook, which gather people who deliberately want to share their own experiences with the disease and learn from others' experiences, were more open towards the idea of being approached and recruited within such groups.

These insights indicate that patients who were already active on social media and found it useful for their personal disease management were more open to being recruited via social media. This led us to the hypothesis: *(H1) The more patients use social media (for Hepatitis B), the higher their acceptance of using social media as a recruitment tool for clinical (Hepatitis B) studies.*

3.1.2 Digital literacy

The patients we interviewed represented a variety of levels regarding social media literacy. While some have had very limited contact with social media as such, others were very active on social media. One patient even described social media content management as part of their daily job. Another had conducted a research online questionnaire for which they were recruiting online. Analysing the interviewee's accounts about their experience with social media, and partially their usage habits, we found a scattered connection to social media recruitment acceptance: those who were considered to have higher digital literacy skills were, in some instances, likely to accept social media as a recruitment tool for clinical Hepatitis B studies, because they perceived other forms of recruitment as outdated:

> "I think we are living in a time that you have to use social media because if you don't use it, […] sending a letter or put[ting it] in the newspaper, will not help you." (patient 6)

On the other end of the spectrum, however, patients with very low digital literacy skills and relatedly very little reported use of social media, or digital media in general, in some instances had difficulties delimiting the concept of social media as such. Presumably, their less nuanced understanding of social media as a concept makes them less strictly opposed to being recruited for a clinical study via social media. One patient, for example, favoured personal contact for study recruitment at first but then revised their statement and reported that being helped was even more important than personal contact:

> "Yes definitely. If it was something important it would be best if we met at a clinic, or I don't know where this study is being done... But even via Facebook or Messenger. [...] Yeah, actually never mind, I don't care actually." (patient 2)

While the interviews suggested a connection between the acceptance of social media recruitment for clinical hepatitis B studies and digital literacy, it remained unclear whether acceptance was higher with high or low digital literacy. Consequently, we tested for a correlation of *(H2) Digital literacy is associated with social media acceptance*.

3.1.3 Interest in clinical studies

Some participating patients expressed particularly high interest in participating in clinical studies about Hepatitis B. One patient explained to us that they were "very, very happy to support studies." (patient 5), and another told us: "I actually want to help. So, that's why I get in" (patient 6). Patients like this, who reported an increased willingness to participate in clinical studies in general, seemed more susceptible to social media as a recruitment tool, too.

Another patient perceived it as beneficial that online recruitment made them less dependent on their doctor to refer them to the study:

> I don't know if my doctor is even internet-savvy, he's a bit older. And well, then I thought, I have to see for myself because I'm not sure how competent he is with such things. What I mean is, it would be nicer if I […] could google for [a clinical trial], land on a platform, search for [relevant studies], see all the information and can get in touch right away and say: 'Hey, I am interested in your study. I would like to participate. Because in my case, the […] specialists didn't even know that this [study] existed. […] That's stupid and got me pretty upset." (patient 3)

None of the patients interviewed reported that they were generally against participation in clinical studies. This is likely a recruitment bias of this qualitative interview study, which made it difficult to interrogate if patients who are less accepting of clinical studies are also less accepting of social media recruitment. Yet, based on the apparent influence of this aspect in two of six patient interviews, we formulated the hypothesis: *(H3) The more patients are interested in clinical studies, the more they accept social media as a recruitment tool for clinical Hep B studies*.

3.1.4 Trust

The role of trust in healthcare professionals, social media platforms, and other recruitment channels was a very salient aspect of all interviews. Illustrating this, one participating Hepatitis B patient stated as a reason for being against social media recruitment:

> "I just feel such a distrust of social media. Any information I share there, I'm not completely comfortable with / It's just not a safe way for me to share information." (patient 4)

Other patients were more open to social media recruitment if they knew the source of the advertisement and assigned relevant expertise to them:

> "It would be okay for me [if someone would contact me on social media to ask whether I would like to meet for a clinical study, as long as] the person is qualified in that direction and is well versed in this expertise." (patient 2)

> "[…] recruiting is normally working if the person that suggests it is a person that you trust or you know. So because she was a person I knew from [redacted], then I clicked the link and I got in. Normally we know, of course, that social media is also a trap for many, I don't know, viruses and this kind of thing. So you don't open everything if you don't trust the link. […] If I would see it on, I don't know, social media and as we know, because you have these cookies that you accept, then immediately, they know that you have something or you are looking for some article. Then this kind of things will pop up. Again, it's all about trusting links. I'm not sure how much I will get in something that is suggesting from just because I click on a link." (patient 6)

More implicitly, another patient emphasized that the clinical setting was the place for them to discuss things in the context of Hepatitis B, not social media:

> "This channel through the [clinic in Germany]… I have a very good opinion of the hospital and I have always been well taken care of there. That is the only channel through which I would talk about my

> condition and about my/ yes. (patient 1)

We analyzed the aspect of trust in a separate publication (currently under review) in detail and hypothesize that: *(H4) The more patients trust information sources, the higher their acceptance of social media recruitment.* The hypothesis was operationalized for trust in medical information sources (H4a) and trust in non-medical information sources (H4b).

3.1.5 Privacy

A particular concern of most patients we spoke with was their privacy. Privacy is a multi-faceted and complex concept, and we found that participants referred to different dimensions of privacy: (1) *Data privacy,* defined as the general attitude towards protective measures that empower patients or users to make their own decisions about who can process their data for which purpose; and (2) privacy related to the *perceived secrecy* of the Hepatitis B diagnosis.

First, regarding data privacy, several patients perceived recruitment via social media as dubious and suspected some form of data leakage or malicious data collection goals behind the reachouts. This view applied irrespectively to how they would be approached on social media (e.g., advertisement banners in their social media timelines, or personal contact requests via social media messengers by healthcare professionals). For example, one patient who reported on being in the process of decreasing their social media usage to protect their privacy also said that if someone contacted them on social media regarding clinical study participation, they would “find that very strange, because [I] would ask [my]self, where did they get this information?” and reported that they would feel that this “would rob quite a lot of privacy” (patient 5). Another patient, who reported using WhatsApp as their only social media, explained that by saying that they “consider social media to be useful in some instances”, however, they continued: “It's too risky for me with my private data and so much advertising. This, for me, trumps all advantages of social media recruitment.” (patient 4).

Regarding the second privacy dimension, secrecy, several patients commented on their Hepatitis B diagnosis being a very private, intimate matter:

> “This condition is in my most private, intimate sphere […] And you might be right, I never thought about it in this way, but [me avoiding engaging on social media regarding Hepatitis B] may be related to the fact that content I pass on via WhatsApp can be passed on thousands of times with one click.” (patient 1)

One patient replied to a question regarding their attitude towards being contacted by a study centre via social media that they “would find that difficult”, because:

> “that's just the problem: it ends up on social media. See, if someone writes: ‘Hey, I would like to ask you about your hepatitis B, whether you would participate in a study?’ Then this information is out there on social media. […] That's why I had a very, very good feeling when my doctor approached me about [this interview study] and that it just went through the clinic. If she had said, ‘Look, someone is approaching you via social media’, or something, then I would have said no, right? Because I wouldn't have wanted to, because these data/social media make money because they have data. They run the ads based on your data and what you type in there or what you say or whatever. And I don't want that associated with my disease.” (patient 5)

These findings led us to the hypothesis: *(H5) The more patients value privacy, the lower their acceptance of using social media as a recruitment tool for clinical Hepatitis B studies.* The hypothesis was operationalized for secrecy (H5a) and data privacy (H5b).

3.1.6 Perceived stigma

Several interviewed Hepatitis B patients reported fear of being stigmatized if their social environment found out about their diagnosis as an important reason against social media recruitment. One patient, who mentioned that only their closest family members knew about their diagnosis, expressed fear that other people learning the diagnosis would lead to social exclusion:

> “A broken leg or surgery on the knee or hip. This is apparent to everyone. And everyone assumes that it will heal at some point and that there is no potential infectious danger from these people. Whereas in the case of infectious diseases, no one can assess that, and people get socially excluded very quickly. […] And this is why I am so cautious with my data.” (patient 1)

A similar view was shared by patient 5. Another patient added that perception of stigma differed depending on the context:

> I come from [Eastern European country], I have moved to Germany. So here the mentality is a little bit different. If you say to someone, I have Hepatitis, he is okay with it. He says: "Oh, is not a problem. Normally here we are vaccinated against it." If you are going to [Eastern European country] and say: "I have Hepatitis B", it's like you have a huge disease that can just be taken by a handshake [laughs]. And so I think that's why I'm going on the conservative site. (patient 6)

The connection between the stigma connected to Hepatitis B and the social-media-connected perceived privacy risks established by several interview participants led us to the hypothesis: *(H6) The higher the perceived stigma of patients, the lower their acceptance of social media as a recruitment tool for clinical Hep B studies*.

3.2 Survey results

3.2.1 Participant characteristics

Across all study centres, an estimated number of 939 Hepatitis B patients were incoming during the study period. A total of 285/939 patients (30,4%) received the questionnaire and 207/285 (72,6%) were sent back to us. On 12 questionnaires, the box required to confirm patient consent was not ticked, leading to a total number of 195 eligible questionnaires (Table S2). Table 2 displays the characteristics of the Hepatitis B patients who participated in the study.

More than half of the participants were aged between 30 and 49 years. Just above half reported having lower educational degrees than Abitur (German equivalent to a high school degree). More than half of the participants had another mother tongue than German (only). All participants had a chronic Hepatitis B infection, as per the inclusion criterion of this study.

Table 2: Participant characteristics.

Total	195	100,0%
Gender		
Male	101	51,8%
Female	88	45,1%
No answer	6	3,1%

Age		
18-29	16	8,2%
30-39	50	25,6%
40-49	58	29,7%
50-59	38	19,5%
60+	24	12,3%
No answer	9	4,6%
Education: Highschool diploma		
Yes	71	36,4%
No	110	56,4%
No answer	14	7,2%
Mother tongue *(multiple answers possible)*		
German	101	51,8%
Other	111	56,9%
No answer	12	6,2%

3.2.2 Description of scales

Overall, we used seven scales that were measured through several items by a 5-point Likert scale (see Table 3 and Table S3).

Table 3: Description of scales.

	N		**No of items**	**Minimum**	**Maximum**	**Mean**	**Median**
	Valid	**Missing**					
General social media usage	195 (100%)	0 (0%)	8	0	32	11,22	11
Social media literacy (H2)	174 (89,2%)	21 (10,8%)	14	0	56	37,58	41
Hepatitis B-related social media use (H1)	181 (92,8%)	14 (7,2%)	6	0	24	5,22	3
Interest in clinical studies (H3)	187 (95,9%)	8 (4,1%)	2	0	8	5,53	6
Trust in medical information sources	180 (92,3%)	15 (7,7%)	4	0	16	10,27	11
Trust in non-medical information sources (H4)	175 (89,7%)	20 (10,3%)	7	0	28	8,36	8,5
Acceptance of SMR (DV)	178 (91,3%)	17 (8,7%)	4	0	16	6,48	6
Secrecy (H5a)	185 (94,9%)	10 (5,1%)	2	0	8	2,25	2
Data privacy (H5b)	186 (95,4%)	9 (4,6%)	2	0	8	6,25	7
Perceived stigma (H6)	180 (92,3%)	15 (7,7%)	6	0	24	5,52	3,5

Notes: Items were measured through a 5-point Likert Scale, ranging from 0 (completely disagree) to 4 (completely agree). DV = Dependent Variable.

The Social Media Acceptance (SMA) scale ranged from 0 to 16 (mean=6,48±3,032, Table 3). While 56 respondents (28.7%) rejected social media recruitment with an SMA score of < 5, 20 respondents (10.2%) accepted social media recruitment with an SMA score of > 11 (Figure 1A). The SMA scale consisted of two subscales: the perceived usefulness of social media recruitment (min=0, max=8, mean=3,80±2,18, Figure 1B) and the intention to use social media recruitment (min=0, max=8, mean=2,69±2,10, Figure 1C).

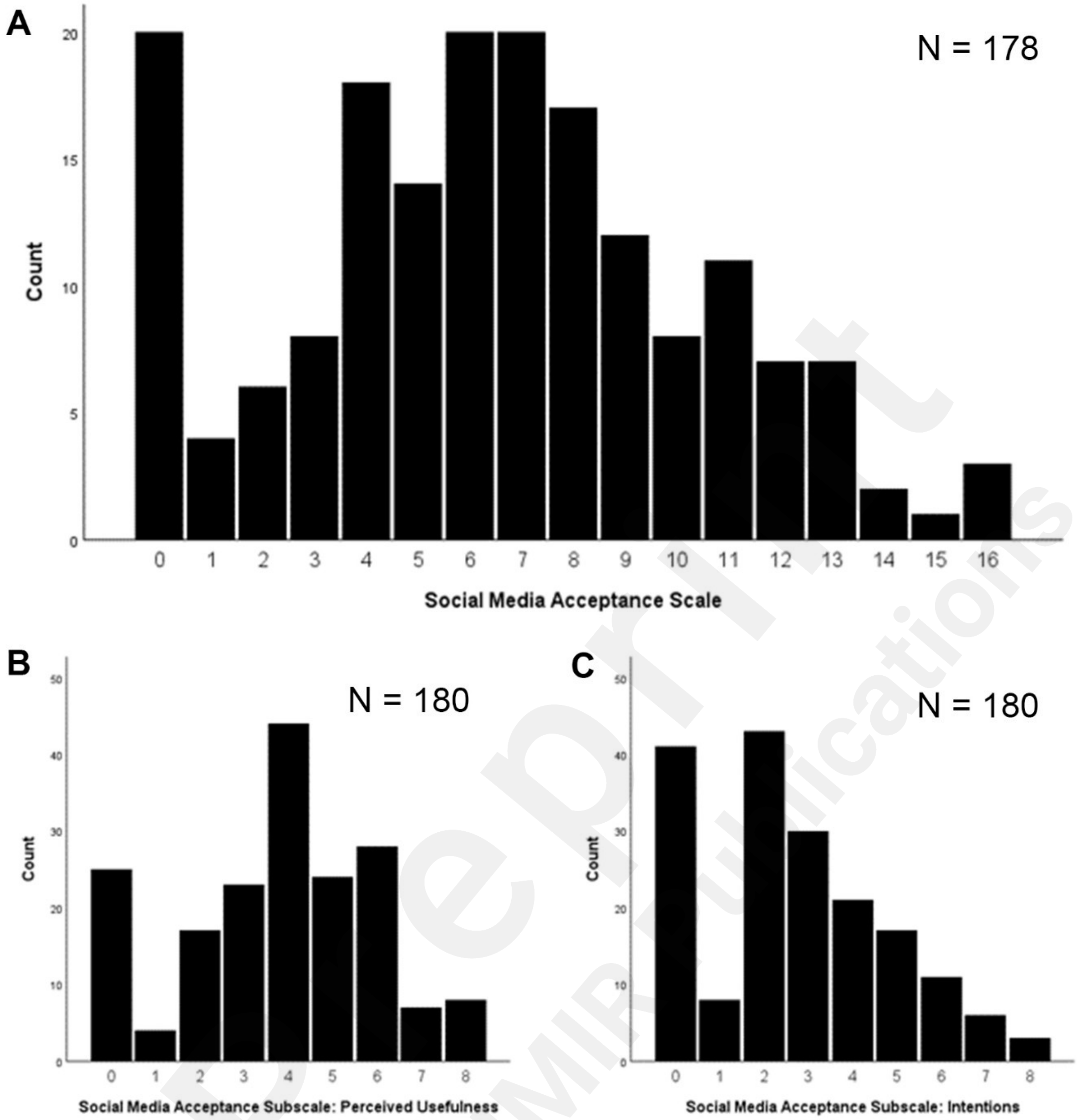

Figure 1: Social media acceptance among Hepatitis B patients in Germany. The higher the scale, the higher the acceptance.

3.2.3 Regression analysis

Using multiple linear regression analyses, we evaluated the predictors of participants' acceptance of social media as a recruitment tool for clinical Hepatitis B studies. Testing the statistical significance of the overall model fit, F-test indicated that the predictors included in the model significantly contributed to the explanation of the dependent variable (Table 4). Regression analysis revealed that social media use for Hepatitis B, interest in clinical studies, trust in non-medical information sources, and Hepatitis B secrecy independently predicted acceptance of social media as a recruitment tool for clinical Hepatitis B studies. More precisely, the higher the social media use for Hepatitis B, the higher the interest in clinical studies, the more trust in non-medical information sources, and the less secret Hepatitis B, the higher the acceptance of social media as a recruitment tool for clinical Hepatitis B studies (Table 4).

Table 4: Multiple linear regression analysis.

	B	S.E.	Beta	t	P value	Tol.	VIF

Constant	4.007	1.935		2.071	.040		
General social media usage	.060	.051	.098	1.175	.242	.628	1.593
Social media literacy	-.002	.025	-.008	-.096	.924	.600	1.668
Hepatitis B-related social media use	.279	.053	.391	5.299	<*.001*	.804	1.234
Interest clinical studies	.283	.127	.171	2.217	*.028*	.732	1.366
Trust medical information sources	-.601	.683	-.079	-.879	.381	.546	1.830
Trust in non-medical information sources	.252	.058	.359	4.307	<*.001*	.632	1.583
Secrecy	-1.299	.542	-.171	-2.399	*.018*	.861	1.161
Data privacy	-.765	.577	-.099	-1.326	.187	.792	1.262
Perceived stigma	-.003	.048	-.004	-.057	.954	.770	1.299
Age	-.052	.028	-.151	-1.842	.068	.648	1.543
Education	.770	.567	.102	1.357	.177	.782	1.278
Overall model fit: F(11,127) = 9.221, $P < .001$; $R^2 = .444$; $N = 139$							

4 Discussion

We here provide the first empirical inquiry investigating the acceptance of social media recruitment for clinical studies among adult Hepatitis B patients. Social media have been suggested to increase recruitment accrual, particularly for hard-to-reach populations [12,13,21]. Our study provides a more fine-grained contextualization of this potential, suggesting that those who are already active on social media with regard to their condition (confirming H1), have a generally high interest in participating in clinical studies (confirming H3), and trust recruitment channels outside the clinical setting (confirming H4a) are accepting social media recruitment and are recruitable via social media. This conclusion is based on the assumptions that (1) patients are most effectively recruited via social media if they accept this channel as a recruitment method and that (2) people who do not accept this recruitment channel should also not be recruited in this way. More than one in four participants rejected being recruited via social media and only one in ten showed high acceptance. These findings indicate that recruitment success via social media might be limited among Hepatitis B patients in Germany and underline the importance of using multiple recruitment channels to facilitate diversity and equitable healthcare access, particularly for vulnerable patient groups [3].

By contrast, social media acceptance was not associated with digital literacy (rejecting H2), data privacy needs (rejecting H5b), and perceived Hepatitis B-related stigma (rejecting H6), even though reported secrecy around Hepatitis B diagnosis was a predictor (confirming H5a). Moreover, trust in medical information sources and demographic variables (age, education) as well as the overall frequency of using social media were not associated with social media acceptance. The results for H2 and H4b are not surprising, as the preceding qualitative interviews did not explicitly indicate a linear connection between digital literacy and social media recruitment acceptance. Our study cannot exclude the possibility that there might be a potential non-linear association, but another survey study found that digital literacy did not directly affect the intention to use digital technology [22]. Further, trust is a multi-faceted concept [23,24], which is why the subjects of trust were split into medical information sources and other advertisement channels. Hence, it is not unexpected that trust in medical information sources is not associated with social media acceptance.

The rejection of H5b (data privacy) and H6 (stigma) were more surprising. The scholarly debate around data privacy issues has been very salient: Data ethicists have repeatedly emphasized the issues related to data privacy and transparency in the context of social media usage in the research context [4,5,11]. Also, the European General Data Protection Regulation (GDPR) emphasizes the transparent use of data and the rights of data subjects [25]. Moreover, various scandals (e.g., related to the US presidential election in 2016 and the UK Brexit referendum), diminished users' trust in social media platforms and increased awareness of data privacy in that context [26,27]. A recent population survey conducted in Germany, the United Kingdom, and the United States confirmed high levels of concern regarding data privacy in all included countries [28]. Given these public discussions about social media activities being problematic for data privacy, it is particularly astonishing that data privacy concerns (as operationalized in our study) were not predicting social media acceptance. Indeed, however, the aforementioned scandals have not resulted in a decline in Facebook users [29,30] and studies suggest a poor user awareness of online privacy [31], and fatigue to engage with privacy-related risks [32]. The findings align with discussions around the privacy paradox: It was confirmed in numerous studies that social media users display limited data protection behaviour despite being concerned about their privacy [33-35].

In addition to other survey studies among Hepatitis B showing that Hepatitis B patients perceived or feared stigma, an Indian survey study found that the majority of surveyed Hepatitis B patients were subject to severe stigma and moderate to severe discrimination, with male gender, unemployment, and illiteracy being predictors of discrimination [6]. Other survey studies from Australia, Turkey, and Serbia confirmed the presence of self-reported perception of stigma in 35-47% of Hepatitis B patients and 60-65% of Hepatitis C patients [36,37,10]. An Iranian qualitative study found that Hepatitis B patients conceptualized stigma as both extrinsic (e.g., discrimination, public embarrassment or blame) and intrinsic (e.g. perceived rejection, social isolation, frustration) [8]. Even though this empirical evidence illustrates the relative importance of stigma in the context of Hepatitis B, this did not predict patients’ acceptance of social media recruitment in our study. Instead, our findings suggest that the perceived secrecy of a Hepatitis B diagnosis – which seems to be unrelated to the perception of stigma – is informative on social media recruitment acceptance.

4.1 Limitations

Our survey showed a relatively balanced representation of genders. This aligns with a German serological study from 2011, which indicated no statistically significant difference in the prevalence of acute or chronic Hepatitis B infection in men and women [38]. In terms of age distribution, the survey study covered a diverse range of age groups, mirroring the distribution found in the German serological study [38]. Based on these observations, the survey sample overall is representative of the Hepatitis B population in Germany regarding gender and age.

However, it is essential to consider potential limitations and sources of bias: The recruitment strategy employed, primarily relying on venue-based recruitment within a clinical setting, might introduce selection bias, as it may not fully capture the diverse population that may exist outside such settings. Additionally, the study's restriction to the German language may have impaired the accessibility of the questionnaire for participants who do not have German as their mother tongue. Also, the exclusive focus on a German setting may limit the generalizability of the findings to a broader international context, potentially impacting the study's external validity. Finally, it is important to note, that we have shortened the questionnaire in comparison to its original length after discussion with clinical colleagues, who provided feedback that the questionnaire was too long. As part of this shortening, some validated scales were replaced by self-developed scales, which may have implications for the comprehensiveness and depth of the data collected.

4.2 Conclusions

This study provides the first quantitative data on the acceptance of social media as a recruitment channel for clinical studies. In the context of Hepatitis B in Germany, acceptance of being recruited via social media was very limited. More than one in four participants (28.7%) rejected this recruitment channel. The study sets out to be a reference point for future studies assessing the attitudes and acceptance of social media recruitment for clinical studies. Such empirical inquiries can facilitate the work of researchers designing clinical studies as well as ethics review boards in balancing the risks and benefits of social media recruitment in a context-specific manner.

Relevant for practice, the findings indicate that social media recruitment is particularly accepted in patient populations with high interest in participating in clinical studies. This is particularly the case for diseases with insufficient treatment options and historically neglected diseases with high unmet needs [39]. Using social media as a recruitment channel for studies targeting these patient groups might thus encounter higher acceptance levels than in this study. There was no statistically significant role associated with perceived stigma and data privacy needs among patients, suggesting that these concerns are unrelated to social media recruitment acceptance.

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Declarations of interest

The authors declare no conflicts of interest.

Multimedia appendix of supplementary files

Table S1: Responses per item.

		Valid N	Min	Max	Mean	Std error of mean	Std deviation
Social Media Usage General							
1.01	Whatsapp	195	0	4	3,37		1,286
1.02	Telegram	195	0	4	0,49		1,073
1.03	Youtube	195	0	4	2,24		1,347
1.04	Facebook	195	0	4	1,48		1,660
1.05	Instagram	195	0	4	1,32		1,744
1.06	Pinterest	195	0	4	0,47		0,949
1.07	Twitter	195	0	4	0,25		0,802
1.08	Xing	195	0	4	0,22		0,672
1.09	Linkedin	195	0	4	0,31		0,830
1.10	Snapchat	195	0	4	0,25		0,832
1.11	Reddit	195	0	4	0,13		0,577
1.12	TikTok	195	0	4	0,64		1,291
1.13	Tumblr	195	0	4	0,06		0,421
Digital literacy							
2.01	Ich weiß, wie ich ein Konto in den sozialen Medien erstelle.	194	0	4	3,00	0,104	1,443
2.02	Ich weiß, wie ich mein Konto in den sozialen Medien lösche.	193	0	4	2,82	0,104	1,448
2.03	Ich weiß, wie ich mein Konto in den sozialen Medien deaktiviere.	193	0	4	2,78	0,104	1,449
2.04	Ich weiß, wie ich Inhalte wie Fotos in meinem Konto in den sozialen Medien teile.	190	0	4	3,16	0,090	1,234
2.05	Ich weiß, wie ich unerwünschte Inhalte aus meinem Konto in den sozialen Medien entferne.	188	0	4	2,83	0,098	1,349
2.06	Ich kenne die Copyright-Gesetze, denen die sozialen Medien unterliegen	185	0	4	2,12	0,100	1,362
2.07	Ich weiß, wie ich Konflikten in den sozialen Medien angemessen begegne.	188	0	4	2,46	0,098	1,337
2.08	Ich kenne die Richtlinien für soziale Medien in meinem beruflichen Umfeld.	189	0	4	2,47	0,103	1,413
2.09	Ich weiß, wie ich den Wahrheitsgehalt der in den sozialen Medien geteilten Informationen überprüfe.	188	0	4	2,51	0,098	1,346
2.10	Ich weiß, wie ich verschiedene Informationsquellen zur Überprüfung von Informationen aus den sozialen Medien nutzen kann.	187	0	4	2,73	0,094	1,281
2.11	Ich kann einschätzen, ob eine Information in den sozialen Medien wahr oder falsch ist.	188	0	4	2,61	0,086	1,186
2.12	Plattformen wie Facebook steuern, was ich in den sozialen Medien sehe.	186	0	4	2,31	0,115	1,563
2.13	Informationen, die ich in sozialen Medien poste, sind dauerhaft.	186	0	4	2,40	0,103	1,408
2.14	Die Werbung, die ich in den sozialen Medien sehe, ist speziell auf meine Vorlieben ausgerichtet.	186	0	4	2,55	0,103	1,403

Social Media Usage Hepatitis B							
3.01	Zum Austausch mit anderen Betroffenen.	189	0	4	0,38	0,067	0,923
3.02	Um verlässliche medizinische Informationen zu finden.	188	0	4	1,26	0,089	1,214
3.03	Um auf dem neuesten Stand der Forschung zu bleiben.	186	0	4	1,09	0,085	1,161
3.04	Um von wissenschaftlichen Studien zu neuen Hepatitis B Behandlungen zu erfahren.	188	0	4	1,09	0,088	1,209
3.05	Um Kontakte zu vertrauenswürdigen Wissenschaftlern und Studienleitern zu knüpfen.	187	0	4	0,51	0,072	0,986
3.06	Um behandelnde Ärzt:innen zu finden.	184	0	4	0,98	0,097	1,310
Interest in Clinical Studies							
4.01	Ich bin allgemein bereit an klinischen Studien teilzunehmen.	188	0	4	2,65	0,096	1,313
4.02	Die Teilnahme an klinischen Studien zu Hepatitis B ist mir wichtig.	190	0	4	2,88	0,091	1,259
Trusted Sources							
5.01	Behandelnder Arzt / Ärztin	188	0	4	3,54	0,063	0,861
5.02	Andere medizinische Fachperson (Pflegende, Assistent:innen, administratives Klinikpersonal etc.)	183	0	4	2,78	0,090	1,213
5.03	Andere Patienten	181	0	4	1,56	0,083	1,122
5.04	Plakatwerbung in der Öffentlichkeit	183	0	4	1,26	0,083	1,117
5.05	Zeitungsinserate	185	0	4	1,27	0,080	1,095
5.06	Werbespots im Fernsehen	185	0	4	1,16	0,081	1,100
5.07	Online Plattform (z.B. eine spezialisierte Plattform, die klinische Studien präsentiert)	184	0	4	1,89	0,091	1,234
5.08	Studienspezifische Webseite	183	0	4	2,08	0,097	1,309
5.09	Soziale Medien: Werbebanner	184	0	4	0,95	0,072	0,977
5.10	Soziale Medien: Persönliche Nachricht von einem Ihnen unbekannten Absender	184	0	4	0,44	0,060	0,820
5.11	Soziale Medien: Persönliche Nachricht von der Studienleitung	182	0	4	1,67	0,093	1,258
Acceptance of Social Media Recruitment							
6.01	Soziale Medien eignen sich gut, um Patient:innen auf Studien zu neuen Hepatitis B Behandlungen aufmerksam zu machen.	184	0	4	1,99	0,090	1,226
6.02	Soziale Medien steigern die Erfolgsaussichten von klinischen Hepatitis B Studien.	180	0	4	1,81	0,084	1,123
6.03	Ich würde mich über soziale Medien für eine klinische Hepatitis B Studie anwerben lassen.	181	0	4	1,13	0,084	1,135
6.04	Ich würde soziale Medien nutzen, um mich über klinische Hepatitis B Studien zu informieren.	182	0	4	1,58	0,091	1,227
6.05	Neg: Es ist schwierig für mich, geeignete Kanäle zu finden um mich über klinische Studien zu Hepatitis B zu informieren.	184	0	4	1,97	0,094	1,276
Privacy: Secrecy and data privacy							
7.01	Neg: Meine Familie und Freunde wissen von meiner Hepatitis B Erkrankung.	188	0	4	0,95	0,084	1,155
7.02	Meine Hepatitis B Erkrankung ist ein Geheimnis.	186	0	4	1,30	0,094	1,288

7.03	Ich achte darauf, dass ich in den sozialen Medien nichts über meine Hepatitis B Erkrankung bekannt gebe, weil ich befürchte, dass die Plattform diese Informationen sammelt und speichert.	186	0	4	2,73	0,111	1,516
7.04	Ich möchte, dass meine medizinischen Daten im Zusammenhang mit meiner Hepatitis B Erkrankung besonders gut geschützt werden.	189	0	4	3,52	0,066	0,908
Perceived Stigma							
8.01	Die Reaktion anderer Menschen auf meine Hepatitis B Infektion hat mich verletzt.	186	0	4	1,39	0,096	1,303
8.02	Manche Menschen vermeiden es, mich zu berühren, sobald sie von meiner Hepatitis B Infektion erfahren haben.	186	0	4	1,05	0,090	1,223
8.03	Manche Menschen wollen mich nicht mehr in der Nähe ihrer Kinder haben, sobald sie von meiner Hepatitis B Infektion erfahren.	185	0	4	0,82	0,080	1,091
8.04	Andere Menschen sind körperlich vor mir zurückgewichen, als sie erfuhren, dass ich Hepatitis B habe.	185	0	4	0,85	0,083	1,125
8.05	Ich habe aufgrund ihrer Reaktionen auf meine Hepatitis B Erkrankung aufgehört, mich mit manchen Leuten zu treffen.	185	0	4	0,65	0,085	1,152
8.06	Die Leute scheinen Angst vor mir zu haben, sobald sie von meiner Hepatitis B Infektion erfahren.	183	0	4	0,92	0,089	1,202

Supplementary methods

Response rate

Table S2: Response rate.

	Munich	**Hannover**	**Leipzig**	**Total**
Data collection period	4 June 2022 - 30 April 2023 (11 months)	23 Aug 2022 – 17 April 2023 (8 months)	17 Mar 2023 – 31 May 2023 (2,5 months)	4 June 2022 – 31 May 2023 (12 months)
Total no of incoming HepB patients during data collection period	308 (28 per month)	576 (72 per month)	55 (22 per month)	939
Response rate I (based on incoming patients)	16,9%	25,9%	10,9%	22,0%
Total no of questionnaires distributed	127	152	6	285
Response rate I (based on no. of questionnaires distributed)	40,9%	98,0%	100,0%	72,6%
Questionnaires received	52	149	6	207
Questionnaires excluded due to lack of consent	-7	-5	0	-12
Included questionnaires	45	144	6	195

Assumptions checks for regression analyses

Cook’s distance indicated that the data contained no outliers (highest value = .682), suggesting no individual cases were unduly influencing the model. Collinearity statistics (Tolerance, VIF) indicated that multicollinearity was not a concern. Durbin-Watson test indicated that the data met the assumption of independent errors (Durbin-Watson = 2.073). Normal P-P plot of standardized residuals indicated that the data contained normally distributed errors (great majority of points on the line). Scatterplots showed that the relationship between the independent variables and the dependent variable is linear (relationships characterized by a straight line; note, three variables had to be dichotomized to meet this assumption); scatterplots of standardized predicted values showed that the data met the assumption of homoscedasticity (looking like a random array of dots). The data also met the assumption of non-zero variances.

Supplementary results

Table S3: Description of each item of the questionnaire (the original questionnaire was in German).

Item		**N**		**Min**	**Max**	**Mean**	**Median**
		Valid	**Missing**				
Frequency of social media usage							
P1.1	Whatsapp	195	0	0	4	3,37	4
P1.2	Telegram	195	0	0	4	0,49	0
P1.3	Youtube	195	0	0	4	2,24	3
P1.4	Facebook	195	0	0	4	1,48	1
P1.5	Instagram	195	0	0	4	1,32	0
P1.6	Pinterest	195	0	0	4	0,47	0
P1.7	Twitter	195	0	0	4	0,25	0
P1.8	Xing	195	0	0	4	0,22	0
P1.9	LinkedIn	195	0	0	4	0,31	0
P1.10	Snapchat	195	0	0	4	0,25	0
P1.11	Reddit	195	0	0	4	0,13	0
P1.12	TikTok	195	0	0	4	0,64	0
P1.13	Tumblr	195	0	0	4	0,06	0
Social media literacy							
P2.01	I know how to create a social media account.	194	1	0	4	3,00	4
P2.02	I know how to delete my social media account.	193	2	0	4	2,82	3
P2.03	I know how to deactivate my social media account.	193	2	0	4	2,78	3
P2.04	I know how to share content such as fotos in my social media account.	190	5	0	4	3,16	4
P2.05	I know how to remove content from my social media account.	188	7	0	4	2,83	3
P2.06	I know the copyright laws relevant to social media.	185	10	0	4	2,12	2
P2.07	I know how to meet conflicts on social media	188	7	0	4	2,46	3
P2.08	I know the social media guidelines in my professional activities.	189	6	0	4	2,47	3
P2.09	I know how to verify the truthfulness of information shared on social media.	188	7	0	4	2,51	3
P2.10	I know how to use different information sources to verify information from social media.	187	8	0	4	2,73	3
P2.11	I can assess whether information on social media is true or false	188	7	0	4	2,61	3

P2.12	Platforms like Facebook control what I see on social media.	186	9	0	4	2,31	2,5
P2.13	Information I post on social media is permanent.	186	9	0	4	2,40	3
P2.14	The ads I see on social media are specifically targeted to my preferences.	186	9	0	4	2,55	3
Social media usage for hepatitis B							
P3.01	To exchange with other patients	189	6	0	4	0,38	0
P3.02	To find reliable medical information	188	7	0	4	1,26	1
P3.03	To keep up with the latest research results	186	9	0	4	1,09	1
P3.04	To learn about new clinical studies for new treatment options for Hepatitis B.	188	7	0	4	1,09	1
P3.05	To get in touch with trustworthy researchers and study coordinators.	187	8	0	4	0,51	0
P3.06	To find treating physicians.	184	11	0	4	0,98	0
Willingness to participate in clinical trials							
P4.01	I am generally willing to participate in clinical trials	188	7	0	4	2,65	3
P4.02	Participating in clinical trials for Hepatitis B is important to me.	190	5	0	4	2,88	3
Trusted information sources							
P5.01	Treating physician	188	7	0	4	3,54	4
P5.02	Other medical professionals (nurses, assistants, administrative hospital staff, etc.)	183	12	0	4	2,78	3
P5.03	Other patients	181	14	0	4	1,56	2
P5.04	Public poster ads	183	12	0	4	1,26	1
P5.05	Newspaper ads	185	10	0	4	1,27	1
P5.06	TV ads	185	10	0	4	1,16	1
P5.07	Online platforms (specialized clinical trial platforms)	184	11	0	4	1,89	2
P5.08	Study-specific website	183	12	0	4	2,08	2
P5.09	Social media ads	184	11	0	4	0,95	1
P5.10	Social media: Personal message from an unknown source	184	11	0	4	0,44	0
P5.11	Social media: Personal message from the study leader	182	13	0	4	1,67	2
Acceptance of social media recruitment							
P6.01	Social media are well suited to make patients aware of studies on new hepatitis B treatments.	184	11	0	4	1,99	2
P6.02	Social media increase the likelihood of success in hepatitis B clinical trials.	180	15	0	4	1,81	2
P6.03	I would be recruited via social media for a hepatitis B clinical trial.	181	14	0	4	1,13	1
P6.04	I would use social media to learn about hepatitis B clinical trials.	182	13	0	4	1,58	2
P6.05	It is difficult for me to find	184	11	0	4	1,97	2

	appropriate channels to learn about hepatitis B clinical trials.						
Secrecy							
P7.01	My family and friends know about my Hepatitis B infection.	188	7	0	4	3,05	4
P7.02	My hepatitis B infection is a secret.	186	9	0	4	1,30	1
Data privacy							
P7.03	I am careful not to disclose anything about my hepatitis B infection on social media for fear that the platform will collect and store this information.	186	9	0	4	2,73	3
P7.04	I want my medical data in connection with my illness to be particularly well protected.	189	6	0	4	3,52	4
Perceived stigma							
P8.01	Other people's reactions to my hepatitis B infection hurt me.	186	9	0	4	1,39	1
P8.02	Some people avoid touching me as soon as they find out about my my hepatitis B infection.	186	9	0	4	1,05	1
P8.03	Some people don't want me around their children once they learn about my hepatitis B infection.	185	10	0	4	0,82	0
P8.04	Other people physically backed away from me when they learned that I had hepatitis B.	185	10	0	4	0,85	0
P8.05	I stopped seeing some people because of their reactions to my hepatitis B disease.	185	10	0	4	0,65	0
P8.06	People seem to be afraid of me as soon as they find out about my hepatitis B infection.	183	12	0	4	0,92	0

Notes: Items were measured through a 5-point Likert Scale, ranging from 0 (completely disagree) to 4 (completely agree).

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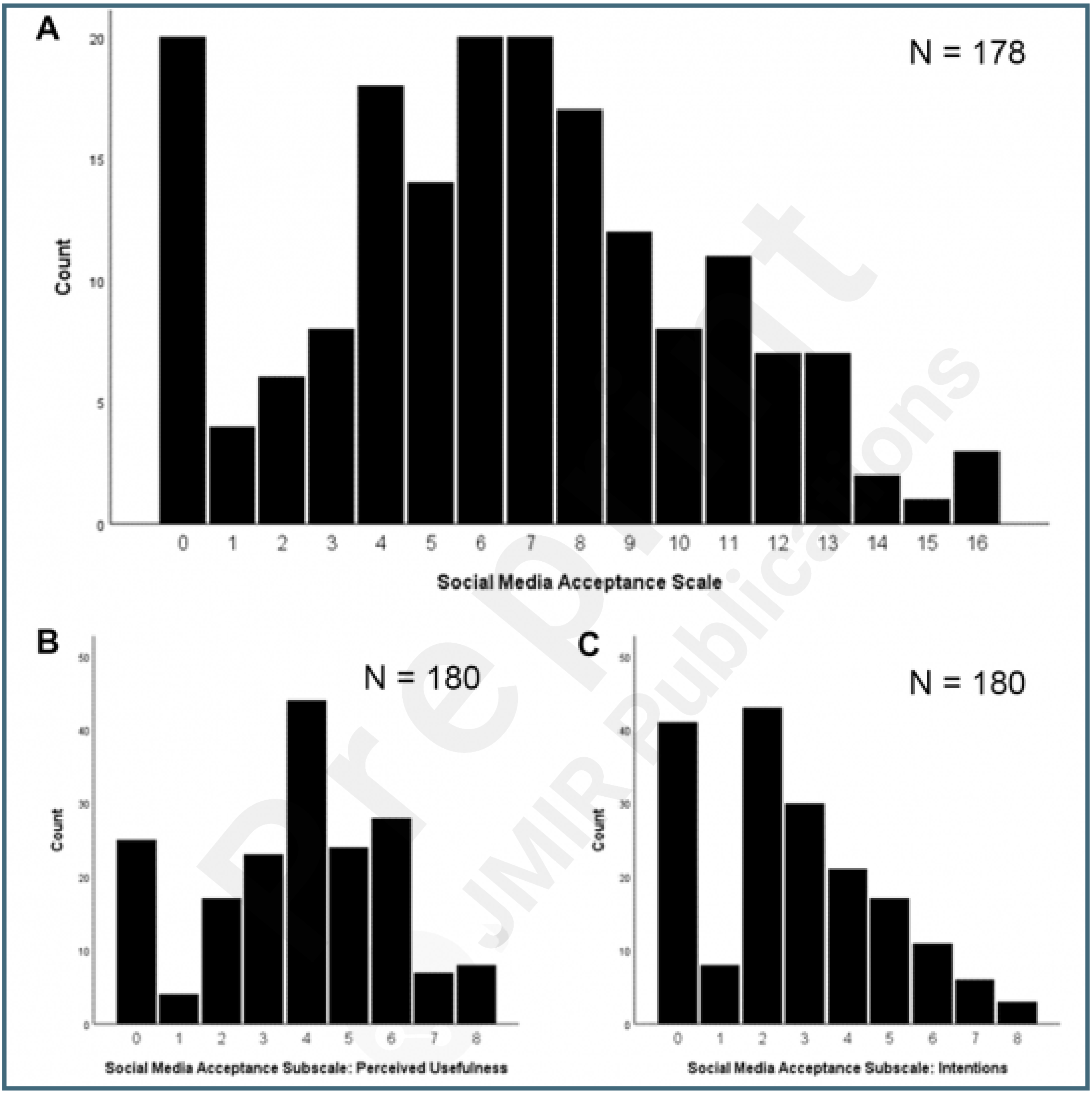
Supplementary Files

Figures

Social media acceptance among Hepatitis B patients in Germany. The higher the scale, the higher the acceptance.



Multimedia Appendixes

Questionnaire.
URL: http://asset.jmir.pub/assets/d784e0bc9ae651710d2e7c47375ef899.pdf