

Section 3

Symptoms and diagnosis

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Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 8 participants (57.14%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and an average of 2.36 symptoms (SD=3.05).

Symptoms before diagnosis

The most common symptoms before diagnosis were being tired, fatigued, or generally weak (n=6, 42.86%), abdominal pain (n=4, 28.57%), muscle or joint aches and pains (n=4, 28.57%), and loss of appetite (n=3, 21.43%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". Median quality of life is presented where five or more participants reported the symptom.

The median quality of life for fatigue was 3.00 (IQR = 2.25), in the "Life was a little distressing" range.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants had no symptoms (50.00%). Others strongly recalled their symptoms or how they came to be diagnosed (33.33%) or had an unclear recollection of their symptoms or how they came to be diagnosed (16.67%).

The most common symptoms leading to diagnosis was fatigue (25.00%), and nausea and vomiting (16.67%). Other symptoms included appetite loss (8.33%), brain fog (8.33%), joint aches (8.33%), muscle aches (8.33%), reflux or digestive problems (8.33%), sleep problems (8.33%), and dark urine (8.33%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having no symptoms or not noticing any symptoms before diagnosis (50.00%) and having symptoms and not seeking medical attention initially (33.33%). Other themes included having symptoms and seeking medical attention relatively soon (8.33%) and being diagnosed as a child (8.33%).

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were being diagnosed by their general practitioner during a check-up related to symptoms (33.33%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (25.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (16.67%). Other themes included being diagnosed in an emergency department (8.33%), being diagnosed from physical as part of immigration tests (8.33%), and not being able to remember (8.33%).

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of hepatitis D and the approximate date of diagnosis with hepatitis D. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 6 participants (8 participants had no symptoms before diagnosis), there were 4 participants (66.67%) that were diagnosed within a year of noticing symptoms, 2 participants (33.33%) diagnosed more than a year from noticing symptoms.

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed immediately at the consultation (n = 2, 14.29%). There were 2 participants (14.29%) that were diagnosed less than one week after diagnostic tests, 3 participants (21.43%) diagnosed between 1 and 2 weeks, 2 participants (14.29%) diagnosed between 2 and 3 weeks, 1 participant (7.14%) diagnosed between 3 and 4 weeks, and 2 participants (14.29%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with hepatitis D. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 and 9 diagnostic tests (median=4.00 , IQR=3.00). The most common tests were blood tests for Hepatitis B infection (n=13, 92.86%), blood tests for Hepatitis D infection (n=13, 92.86%), blood tests for liver function (n=6, 42.86%), and blood tests for Hepatitis C infection (n=5, 35.71%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a general practitioner (GP) (n=8, 57.14%), and there were 6 participants (42.86%) given the diagnosis by a specialist doctor.

Participants were most commonly given their diagnosis in the general practice (GP) (n=8, 57.14%), this was followed by the hospital (n=3, 21.43%), and the specialist clinic (n=3, 21.43%).

Hepatitis Vaccinations

Most participants had a Hepatitis A vaccination (n=10, 71.43%), and a Hepatitis B vaccination (n=9, 64.29%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most commonly participants knew nothing or very little about the condition at diagnosis (75.00%) Other participants described knowing about the condition including causes and risk factors (25.00%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 2 participants (14.29%) who had enough support, 2 participants (14.29%) that had some support but it wasn't enough, and 10 participants (71.43%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 3 participants (21.43%) who had enough information, 5 participants (35.71%) that had some information but it wasn't enough, and 6 participants (42.86%) had no information.

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 7 participants (50.00%) who had no out of pocket expenses, and 5 participants (35.71%) who did not know or could not recall. There were 2 participants (14.29%) that spent between \$50 and \$150.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 5 participants (35.71%) the cost was slightly or not at all significant, and for 2 participants (14.29%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=8, 57.14%). There was 1 participant (7.14%) who brought up the topic with their doctor, and 5 participants (35.71%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Offered liver checks every 6 months

Participants were asked in the online questionnaire if they were offered liver checks at least every 6 months. The majority of participants were offered liver checks every 6 months (n=9, 64.29%)

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (25.00%), and that there was uncertainty around prognosis (25.00%). Other themes included that their prognosis was positive, that their condition is manageable (16.67%), that there was no evidence of disease or that they are in remission (16.67%), that they were monitoring their condition until there is an exacerbation or progression (16.67%), that it being currently controlled (8.33%), and in relation to the risk of liver cancer (8.33%).

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 8 participants (57.14%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and an average of 2.36 symptoms (SD=3.05).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	Number (n=14)	Percent
No symptoms	8	57.14
1 to 2	0	0.00
3 to 4	2	14.29
5 to 6	2	14.29
7 to 8	2	14.29

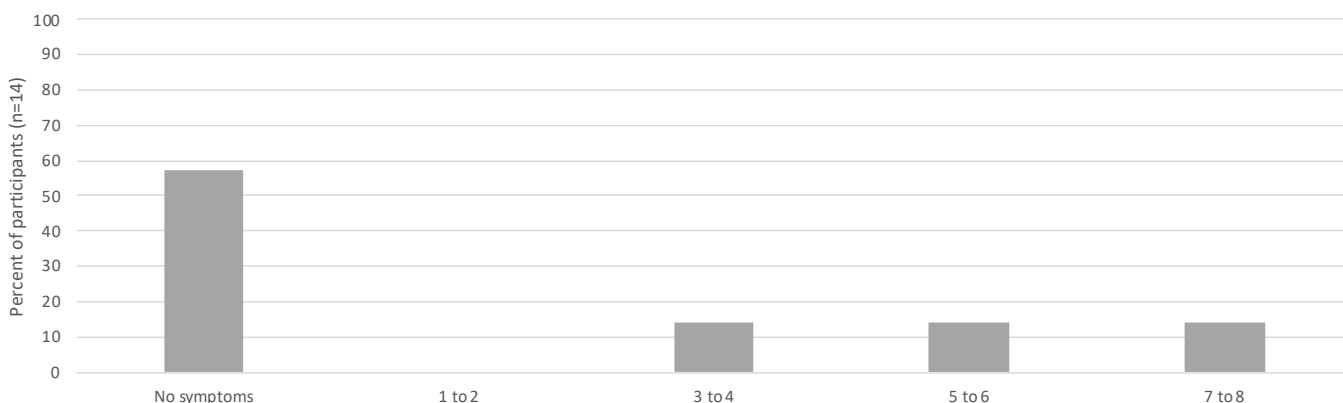


Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms before diagnosis were being tired, fatigued, or generally weak (n=6, 42.86%), abdominal pain (n=4, 28.57%), muscle or joint aches and pains (n=4, 28.57%), and loss of appetite (n=3, 21.43%).

Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". Median quality of life is presented where five or more participants reported the symptom.

Participants were asked a follow up question about their quality of life while experiencing these symptoms.

The median quality of life for fatigue was 3.00 (IQR = 2.25), in the "Life was a little distressing" range.

Table 3.2: Symptoms before diagnosis

Symptom	Number (n=14)	Percent	Quality of life	
			Mean	SD
No symptoms	8	57.14	NA	NA
Tired, fatigued, or generally weak	6	42.86	3.00	2.25
Abdominal pain	4	28.57	NA	NA
Muscle or joint aches and pains	4	28.57	NA	NA
Loss of appetite	3	21.43	NA	NA
Nausea and/or vomiting	3	21.43	NA	NA
Fever	3	21.43	NA	NA
Yellowing skin, or eyes (jaundice)	3	21.43	NA	NA
Swollen abdomen (from a build up of fluid)	2	14.29	NA	NA
Pale, or chalky bowel movements	2	14.29	NA	NA

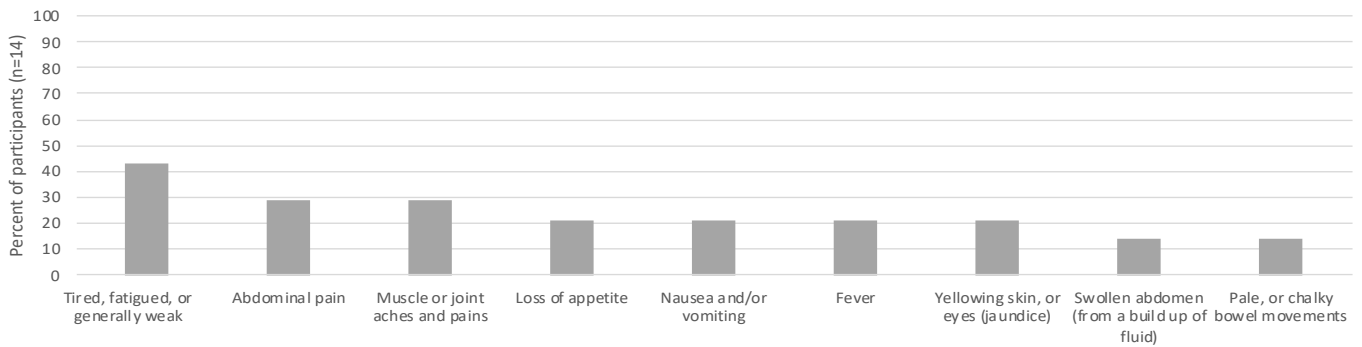


Figure 3.2: Symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants had no symptoms (50.00%). Others strongly recalled their symptoms or how they came to be diagnosed (33.33%) or had an unclear recollection of their symptoms or how they came to be diagnosed (16.67%).

The most common symptoms leading to diagnosis was fatigue (25.00%), and nausea and vomiting (16.67%). Other symptoms included appetite loss (8.33%), brain fog (8.33%), joint aches (8.33%), muscle aches (8.33%), reflux or digestive problems (8.33%), sleep problems (8.33%), and dark urine (8.33%).

Participant describes having no symptoms experienced which led to their diagnosis

Yeah, no symptom at all. I only get to know about it when I apply the visa to come to Australia and then doctor followed up with other test.

Participant 001_2023AUHDV

No, no, it came totally out of the blue.
Participant 007_2023AUHDV

Participant describes having nausea and vomiting which led to their diagnosis

Well, the very first common symptoms I experienced was mainly fatigue and, you know, dark urine and also my stool was affected and also had some other symptoms like a lot of appetite and abdominal pains. So the symptoms kept on coming and I was kind of not really knowing what was happening to me. So it just started little by little to it got severe

Participant 006_2023AUHDV

OK, the symptoms I had were so pretty much nausea and fatigue, tiredness.

Participant 012_2023AUHDV

Participant describes having brain fog which led to their diagnosis

So what happened to me was I felt very unwell. I was working full time and I thought, you know, my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested based on my history. Participant 010_2023AUHDV

Table 3.3: Symptom recall

Symptom recall	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
No Symptoms	6	50.00	4	66.67	2	33.33	4	50.00	2	50.00	2	33.33	4	66.67	1	100.00	5	45.45	1	100.00	5	45.45
Symptom recall strong	4	33.33	2	33.33	2	33.33	2	25.00	2	50.00	3	50.00	1	16.67	0	0.00	4	36.36	0	0.00	4	36.36
Symptom recall unclear	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

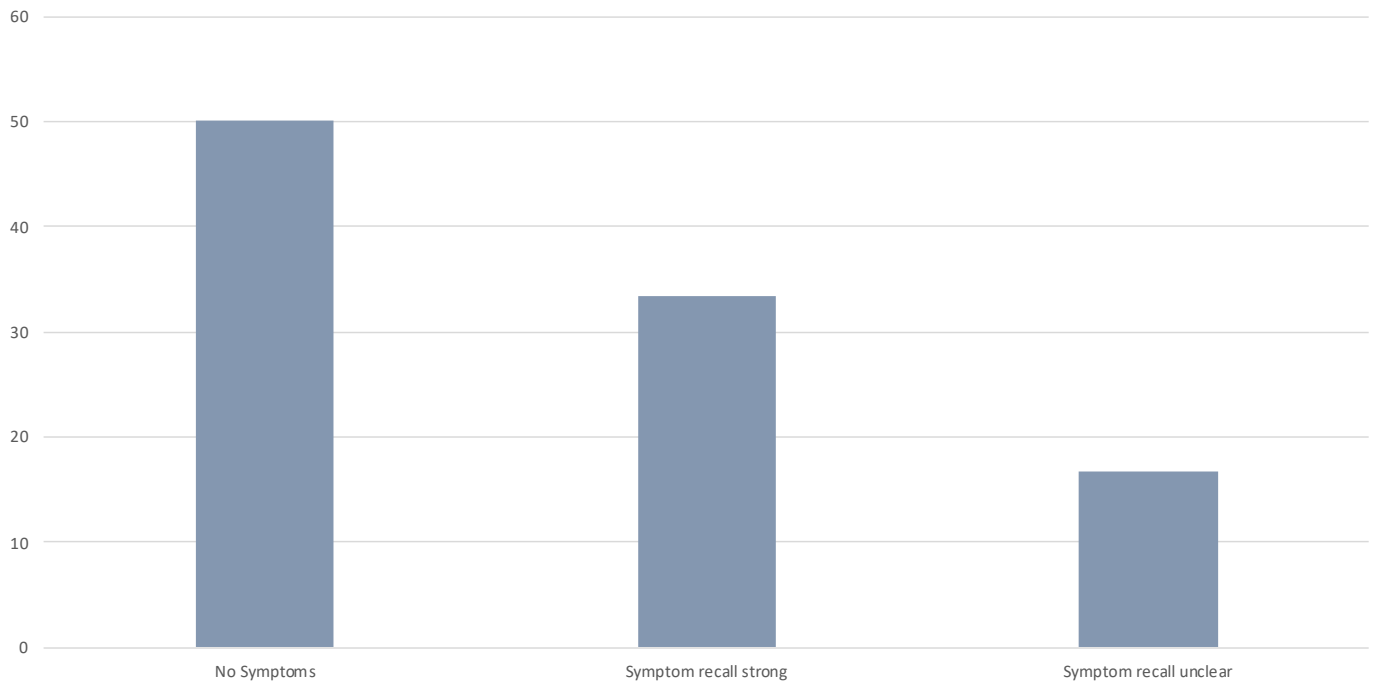


Figure 3.3: Symptom recall

Table 3.4: Symptom recall – subgroup variations

Symptom recall	Reported less frequently	Reported more frequently
No Symptoms	Male Trade or high school	Female University
Symptom recall strong	University	Aged 45 and older Trade or high school

Table 3.5: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes having no symptoms experienced which led to their diagnosis	6	50.00	4	66.67	2	33.33	4	50.00	2	50.00	2	33.33	4	66.67	1	100.00	5	45.45	1	100.00	5	45.45
Participant describes having fatigue which led to their diagnosis	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes having nausea and vomiting which led to their diagnosis	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes having appetite loss which led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having brain fog which led to their diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having joint aches which led to their diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having muscle aches which led to their diagnosis	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having reflux or digestive problems which led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having sleep problems which led to their diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having urine changes - dark which led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having symptoms but does not describe in detail	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not being able to recall the symptoms that led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

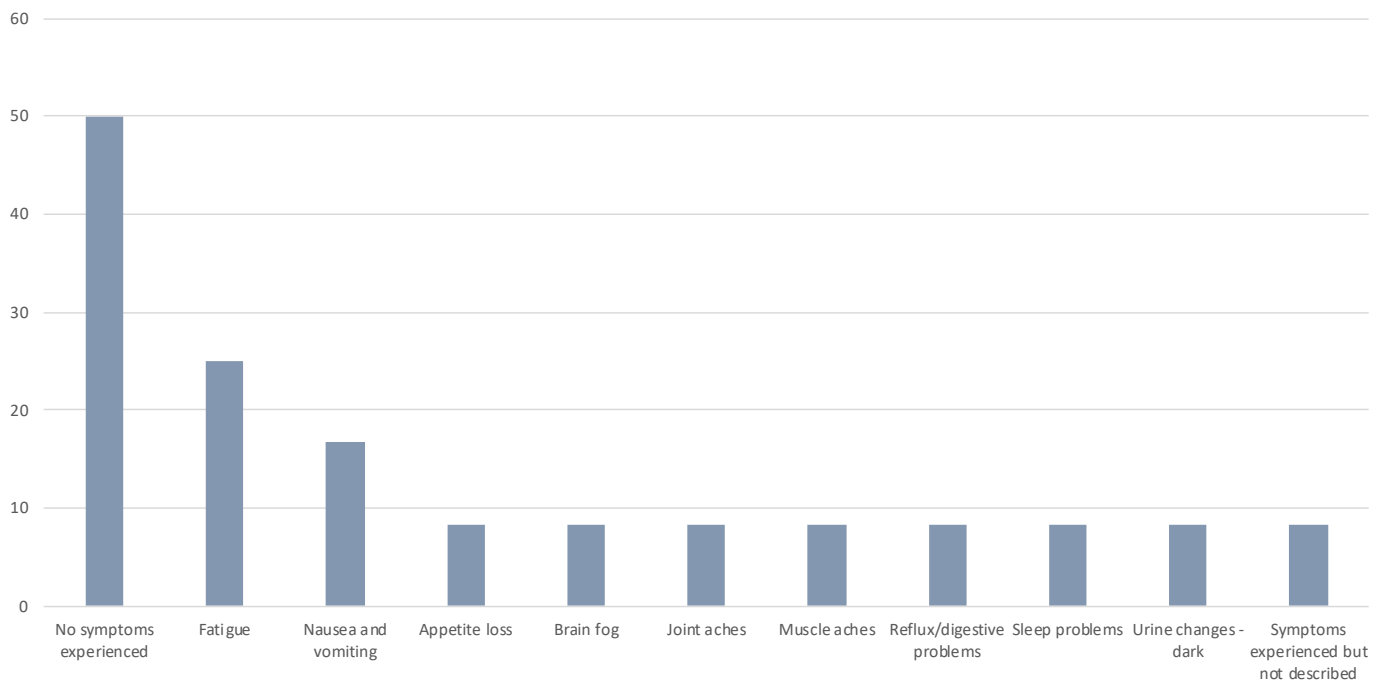


Figure 3.4: Symptoms leading to diagnosis

Table 3.6: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having no symptoms experienced which led to their diagnosis	Male Trade or high school	Female University

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having no symptoms or not noticing any symptoms before diagnosis (50.00%) and having symptoms and not seeking medical attention initially (33.33%). Other themes included having symptoms and seeking medical attention relatively soon (8.33%) and being diagnosed as a child (8.33%).

Participant describes having no symptoms or not noticing any symptoms before diagnosis

I don't think I noticed any immediate symptoms before I was diagnosed. I didn't notice anything.
Participant 004_2023AUHDV

No, no, it came totally out of the blue.
Participant 007_2023AUHDV

Participant describes having symptoms and not seeking medical attention initially

I actually didn't know what was going on with me and I wasn't quite very sure and a little bit scared, but I got recommended by my friend to go see a medical professional. Yeah.
Participant 009_2023AUHDV

INTERVIEWER: Okay. All right, excellent okay. And how long were you suffering with nausea and fatigue?
PARTICIPANT: It might have been months before I was before I actually got to my diagnosis.
Participant 012_2023AUHDV

Participant describes having symptoms and seeking medical attention relatively soon

So what happened to me was I felt very unwell. I was working full time and I thought, you know, my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested based on my history. Participant 010_2023AUHDV

Table 3.7: Seeking medical attention

Seeking medical attention	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes having no symptoms or not noticing any symptoms before diagnosis	6	50.00	4	66.67	2	33.33	4	50.00	2	50.00	2	33.33	4	66.67	1	100.00	5	45.45	1	100.00	5	45.45
Participant describes having symptoms and not seeking medical attention initially	4	33.33	1	16.67	3	50.00	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes having symptoms and seeking medical attention relatively soon	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being diagnosed as a child	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

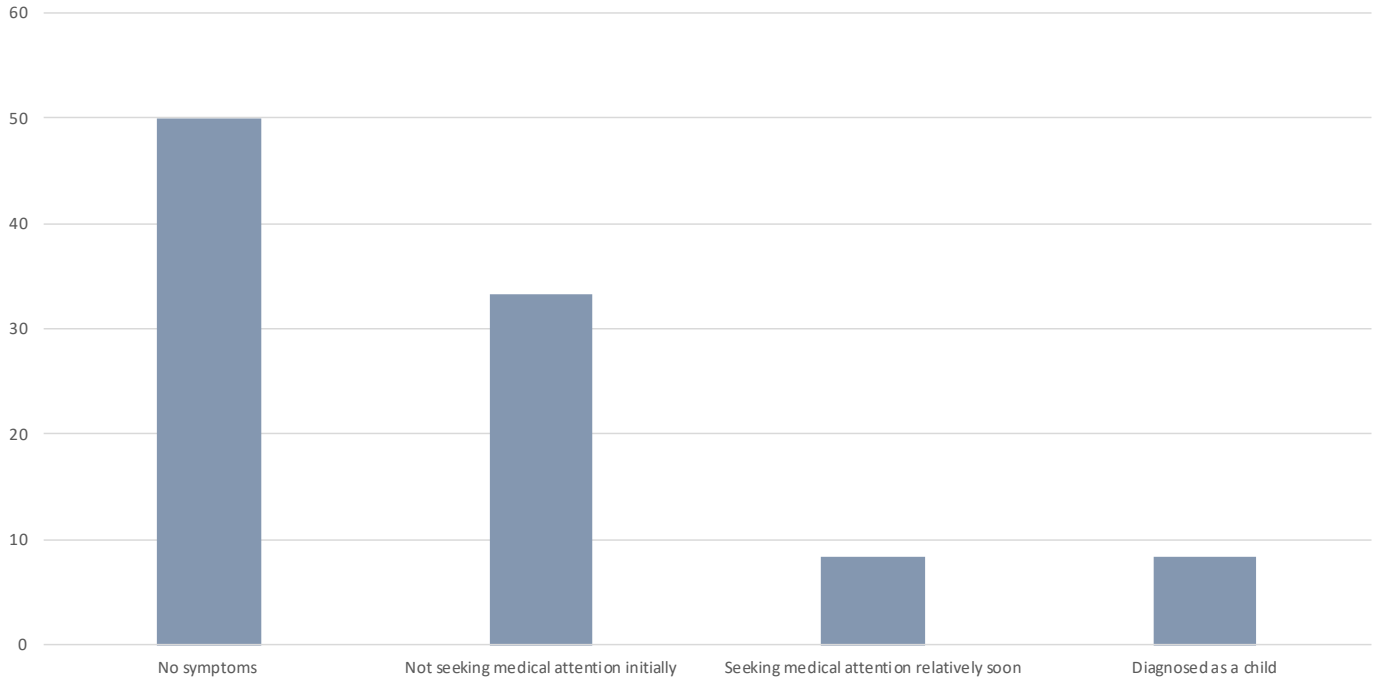


Figure 3.5: Seeking medical attention

Table 3.8: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having no symptoms or not noticing any symptoms before diagnosis	Male Trade or high school	Female University
Participant describes having symptoms and not seeking medical attention initially	Female	Male

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were being diagnosed by their general practitioner during a check-up related to symptoms (33.33%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (25.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (16.67 %). Other themes included being diagnosed in an emergency department (8.33%), being diagnosed from physical as part of immigration tests (8.33%), and not being able to remember (8.33%).

Participant describes being diagnosed by their general practitioner during a check-up related to symptoms

Well, all the procedures was carried out by a doctor, you know, I had to seek medical attention when I noticed all the symptoms and got into the clinic. I was

kind of run...I was given some medication, you know, testing every other thing. Yeah, my it was a kind of blood test. The doctor took blood from veins and he sent it to the lab and then the both result was confirmed. Participant 006_2023AUHDV

OK, I have to my GP and I told him how I was feeling and he got me blood tested for various things I support and it came back and he said I was positive. Participant 012_2023AUHDV

Participant describes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms

OK, I just went to my GP to do some checkup to see if everything was fine. And there was an alteration on my blood testing like my iron was too high. OK. And

then we did extra blood testing that accused the hepatitis.

Participant 005_2023AUHDV

Participant describes a linear diagnosis after being referred to a specialist from their general practitioner

INTERVIEWER: They sent you off to a gastroenterologist.

PARTICIPANT: Yeah, and I got some blood tests
Participant 002_2023AUHDV

I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested for a stomach virus.

Anyway, it came back that I had a virus so I took the

treatment for that and then I still felt unwell... in her wisdom asked me a lot more about my younger life. Not like all my medical history. And I just sort of said...I gave up drinking and abusing substances and she said, oh, what, what kind of wild child did you ever use IV drugs? And I said, yes, I did and she said, have you ever been tested for HIV or hepatitis?... Anyway she said, well let's test you the hepatitis.

Participant 010_2023AUHDV

Participant describes being diagnosed from physical as part of immigration tests

INTERVIEWER: Who ordered them for you? Sorry, which organization did the test? Like ordered?

PARTICIPANT: The test first with the Australian immigration then doctor.

Participant 001_2023AUHDV

Table 3.9: Diagnostic pathway

Diagnostic pathway	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes being diagnosed by their general practitioner during a check-up related to symptoms	4	33.33	1	16.67	3	50.00	3	37.50	1	25.00	1	16.67	3	50.00	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	0	0.00	3	50.00	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes a linear diagnosis after being referred to a specialist from their general practitioner	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being diagnosed in an emergency department	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being diagnosed from physical as part of immigration tests	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant is not able to remember details about diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

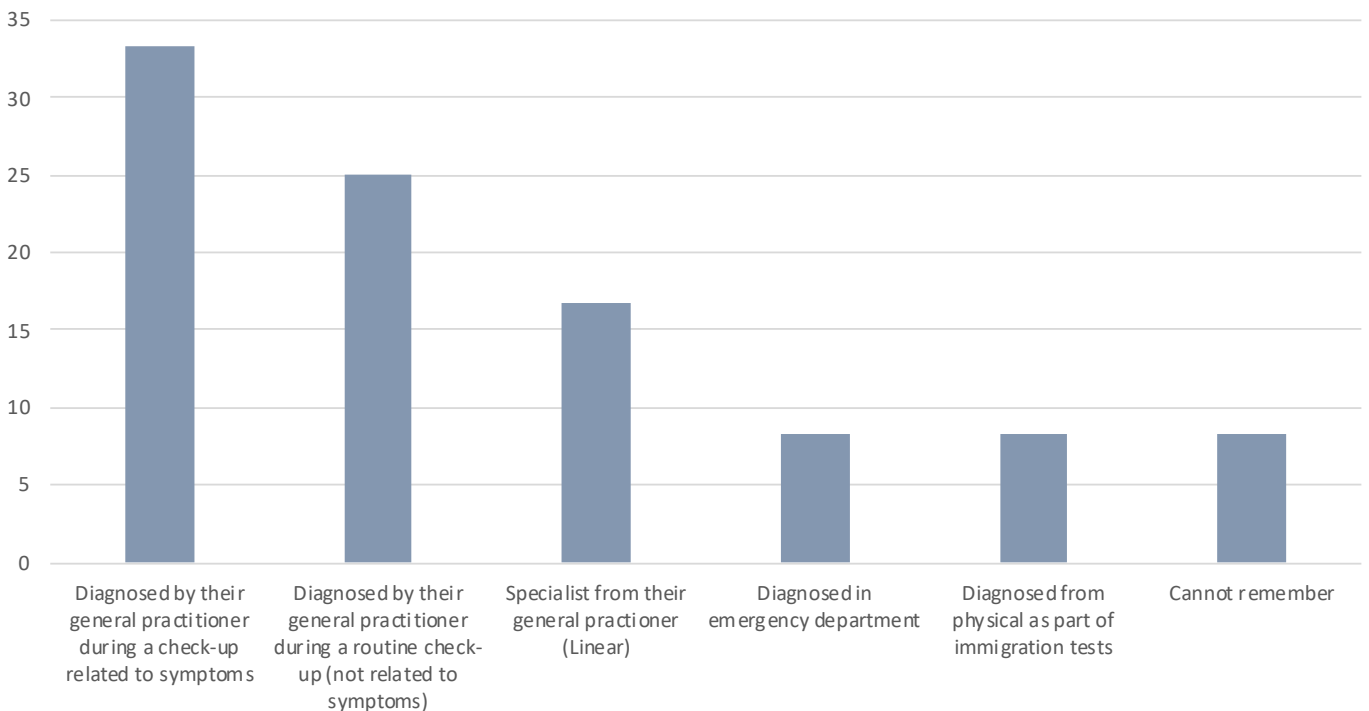


Figure 3.6: Diagnostic pathway

Table 3.10: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being diagnosed by their general practitioner during a check-up related to symptoms	Female	Male
Participant describes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	Trade or high school	University

Timing of diagnosis

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of hepatitis D and the approximate date of diagnosis with hepatitis D. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 6 participants (8 participants had no symptoms before diagnosis), there were 4 participants (66.67%) that were diagnosed within a year of noticing symptoms, 2 participants (33.33%) diagnosed more than a year from noticing symptoms.

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed within a consultation (n = 2, 14.29%). There were 2 participants (14.29%) that were diagnosed less than one week after diagnostic tests, 3 participants (21.43%) diagnosed between 1 and 2 weeks, 2 participants (14.29%) diagnosed between 2 and 3 weeks, 1 participants (7.14%) diagnosed between 3 and 4 weeks, and 2 participants (14.29%) diagnosed more than four weeks after diagnostic testing.

Table 3.11: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=6)	Percent
Within a year	4	66.67
More than a year	2	33.33



Figure 3.7: Time from symptoms to diagnosis

Table 3.12: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=14)	Percent
Diagnosed immediately at the consultation	2	14.29
Less than 1 week	2	14.29
Between 1 and 2 weeks	3	21.43
Between 2 and 3 weeks	2	14.29
Between 3 and 4 weeks	1	7.14
4 weeks or more	2	14.29
Not specified	2	14.29

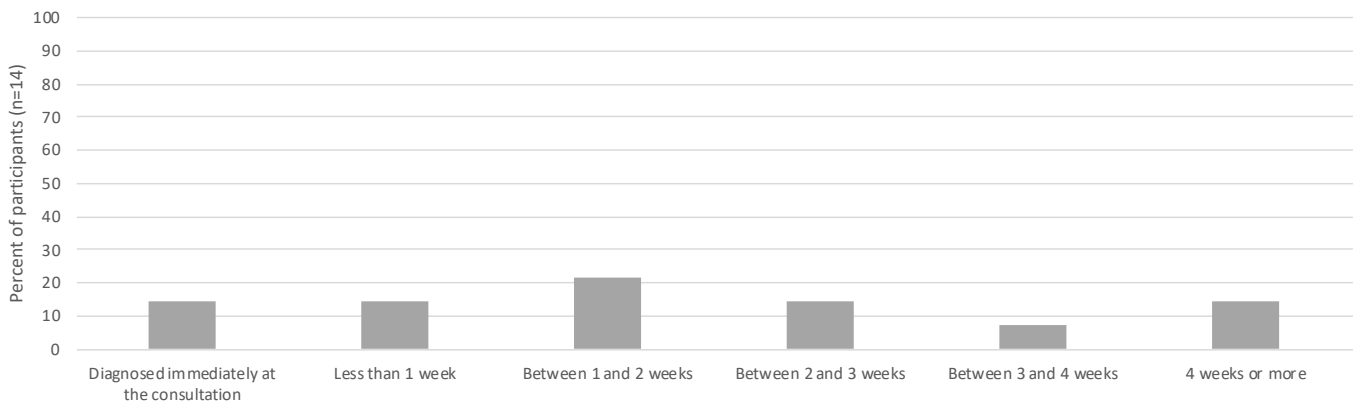


Figure 3.8: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with hepatitis D. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 and 9 diagnostic tests (median=4.00 , IQR=3.00). The most common tests were blood tests for Hepatitis B infection (n=13, 92.86%), blood tests for Hepatitis D infection (n=13, 92.86%), blood tests for liver function (n=6, 42.86%), and blood tests for Hepatitis C infection (n=5, 35.71%).

Table 3.13: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=14)	Percent
1 to 2	4	28.57
3 to 4	6	42.86
5 to 6	2	14.29
7 or more	2	14.29

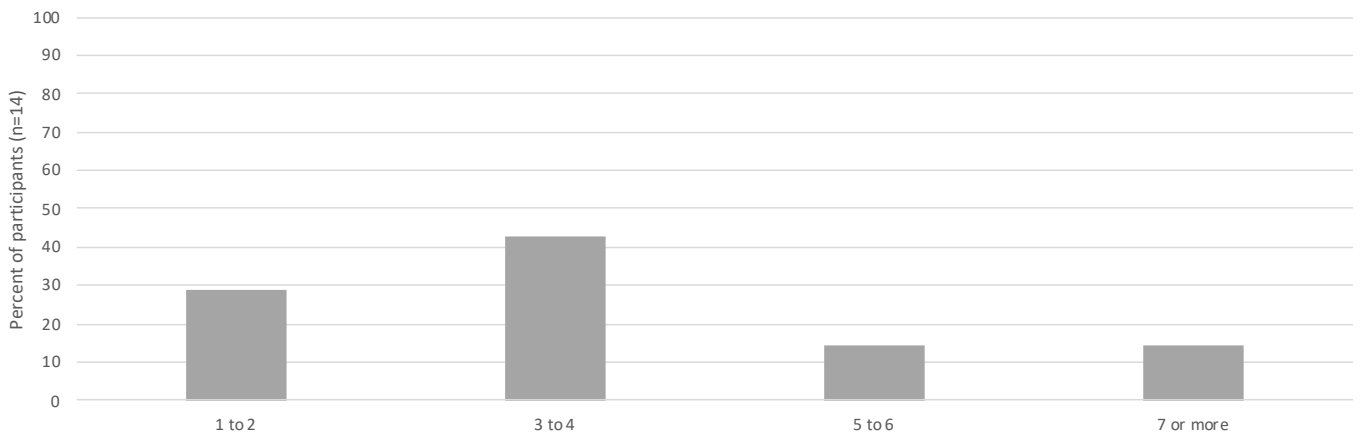


Figure 3.9: Number of diagnostic tests

Table 3.14: Diagnostic tests

Diagnostic tests	Number (n=14)	Percent
Blood tests for Hepatitis B infection	13	92.86
Blood tests for Hepatitis D infection	13	92.86
Blood tests for Liver function	6	42.86
Blood tests for Hepatitis C infection	5	35.71
Physical examinal	5	35.71
Ultrasound	5	35.71
Fibroscan (transient elastography)	4	28.57
Personal and family medical history	3	21.43
Biopsy	2	14.29
Not sure	1	7.14

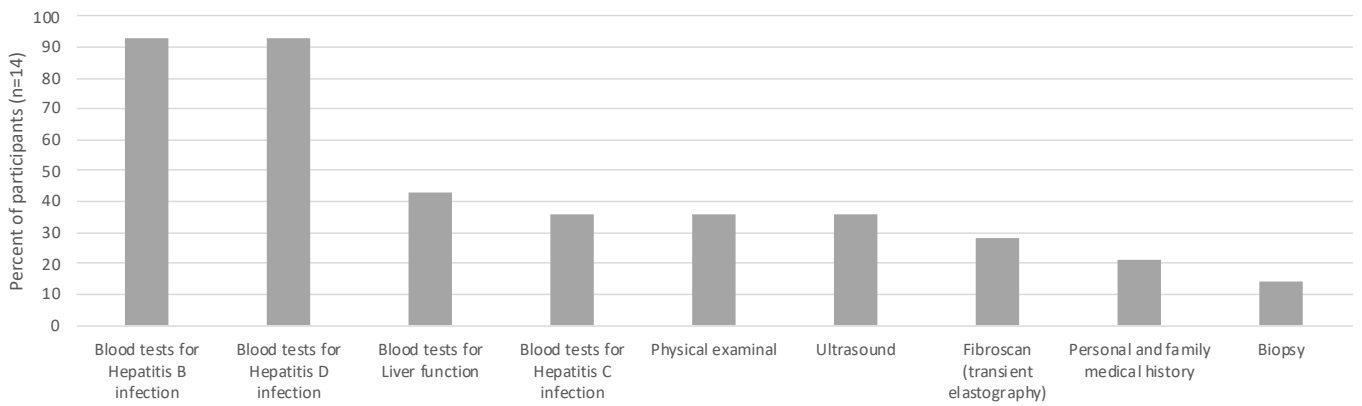


Figure 3.10: Diagnostic tests

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a general practitioner (GP) (n=8, 57.14%),

and there were 6 participants (42.86%) given the diagnosis by a specialist doctor.

Participants were most commonly given their diagnosis in the general practice (GP) (n=8, 57.14%), this was followed by the hospital (n=3, 21.43%), and the specialist clinic (n=3, 21.43%).

Table 3.15: Diagnosis provider

Health professional gave diagnosis	Number (n=14)	Percent
General practitioner (GP)	8	57.14
Specialist doctor	6	42.86



Figure 3.11: Diagnosis provider

Table 3.16 Diagnosis location

Location of diagnosis	Number (n=14)	Percent
General practice (GP)	8	57.14
Hospital	3	21.43
Specialist clinic	3	21.43

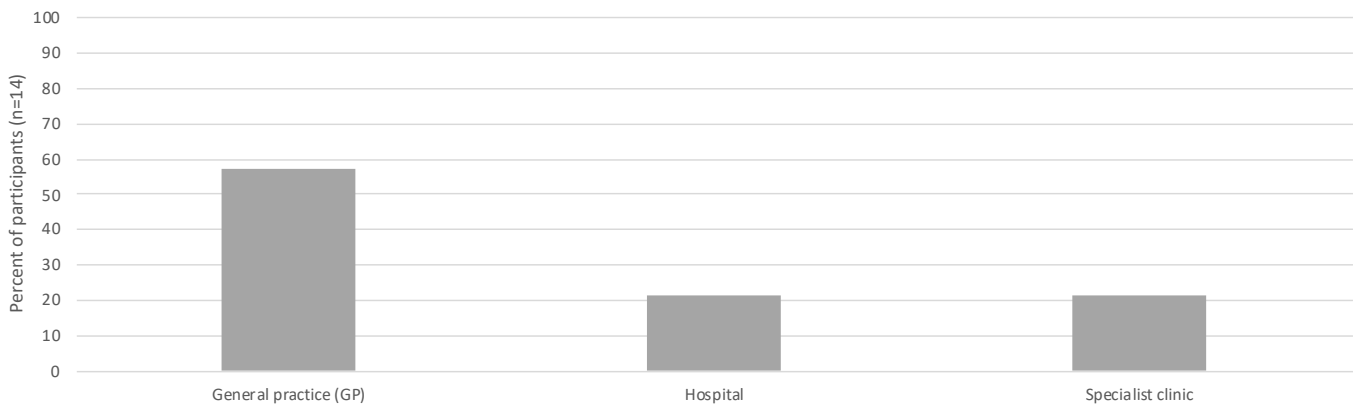


Figure 3.12: Diagnosis location

Type of infection

Type of hepatitis D infection

Participants had Chronic Hepatitis D (n=11, 78.57%), followed by Acute Hepatitis D (n=3, 21.43%).

Hepatitis Vaccinations

Most participants reported having had a Hepatitis A vaccination (n=10, 71.43%), and a Hepatitis B vaccination (n=9, 64.29%).

Table 3.19: Vaccinations for hepatitis

Vaccinations for hepatitis	Number (n=14)	Percent
Hepatitis A	10	71.43
Hepatitis B	9	64.29



Figure 3.15: Vaccinations for hepatitis

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most commonly participants knew nothing or very little about the condition at diagnosis (75.00%) Other participants described knowing about the condition including causes and risk factors (25.00%).

Participant describes knowing nothing or very little about the condition at diagnosis

I wasn't quite sure about it. Yeah. So I quite scared. Yeah.

Participant 009_2023AUHDV

Well, like I said previously, I I didn't know anything about it when I was when I first went to the specialist. But the specialist gave me information about it and then she suggested that I do as much research as I as I could about it. Yeah, so I did.

Participant 010_2023AUHDV

Very little. Very little at all. And I'd have to say, even at that point of diagnosis, they didn't really take the time to explain it to me and how it was all interrelated. It was only kind of subsequently in conversations...that I understood it had something to do with my liver.

Participant 011_2023AUHDV

Participant describes knowing something about the condition including causes and risk factors

I was very limited. I understood that it was a blood to blood, blood disease. So and I felt a lot of shame like. Yeah. So that's pretty much I think what I recall,

maybe even getting one pamphlet, but I don't think there was that much information out there for me at the time to comprehend that. It was just pretty much what the doctors said of reading your results and that was about it.

Participant 004_2023AUHDV

Table 3. 20: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes knowing nothing or very little about the condition at diagnosis	9	75.00	3	50.00	6	100.00	6	75.00	3	75.00	4	66.67	5	83.33	1	100.00	8	72.73	1	100.00	8	72.73
Participant describes knowing about the condition including causes and risk factors	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

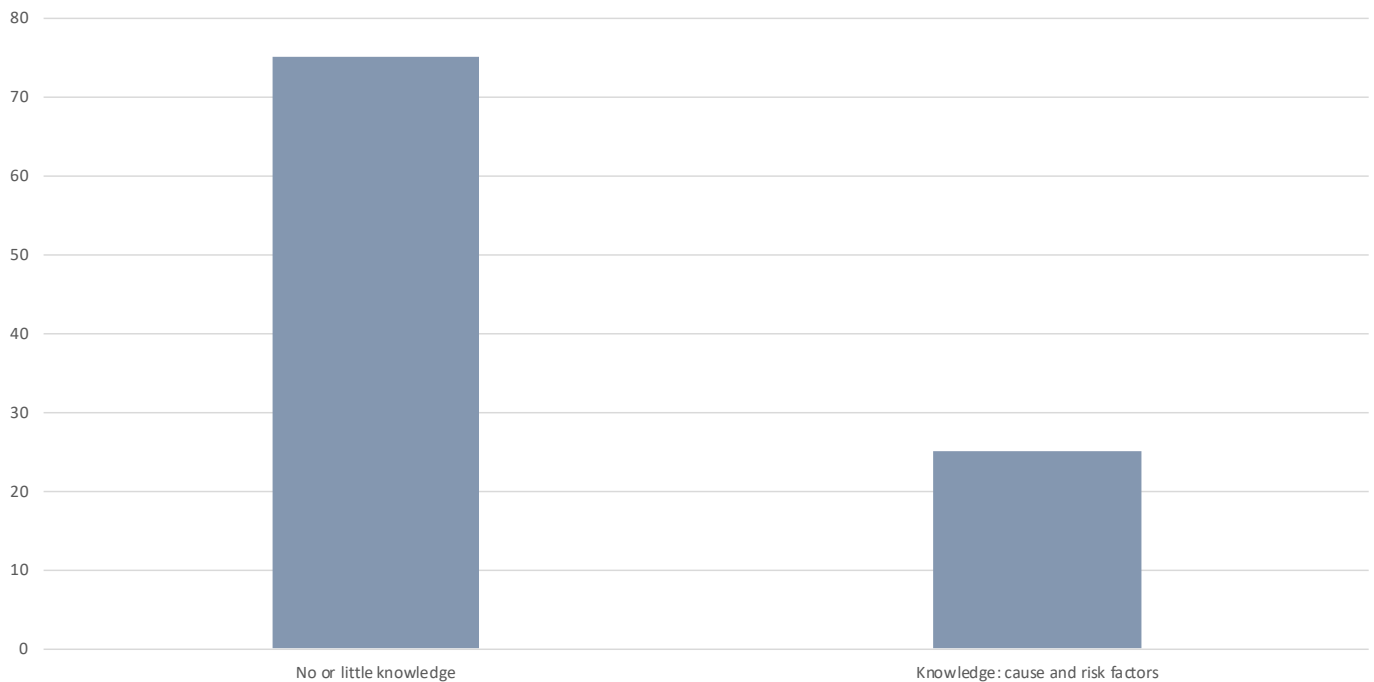


Figure 3.16 Understanding of disease at diagnosis

Table 3.21: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes knowing nothing or very little about the condition at diagnosis	Female	Male

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 2 participants (14.29%) who had enough support, 2 participants (14.29%) that had some support but it wasn't enough, and 10 participants (71.43%) had no support.

Table 3.22: Emotional support at diagnosis

Information at diagnosis	Number (n=14)	Percent
Enough information	3	21.43
Some information but it wasn't enough	5	35.71
No information	6	42.86

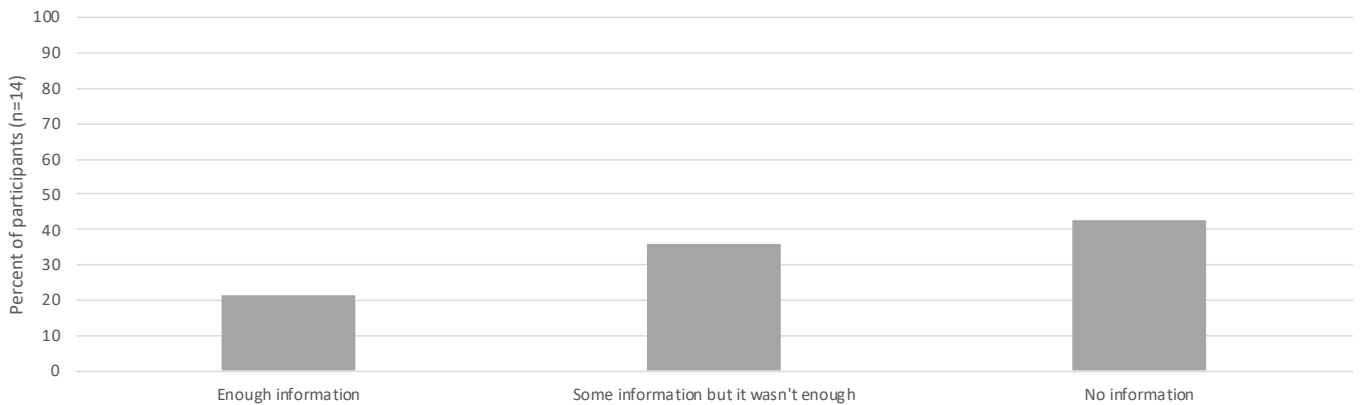


Figure 3.17: Emotional support at diagnosis

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 3 participants (21.43%) who had enough information, 5 participants (35.71%) that had some information but it wasn't enough, and 6 participants (42.86%) had no information.

Table 3.23: Information at diagnosis

Emotional support at diagnosis	Number (n=14)	Percent
Enough support	2	14.29
Some support but it wasn't enough	2	14.29
No support	10	71.43

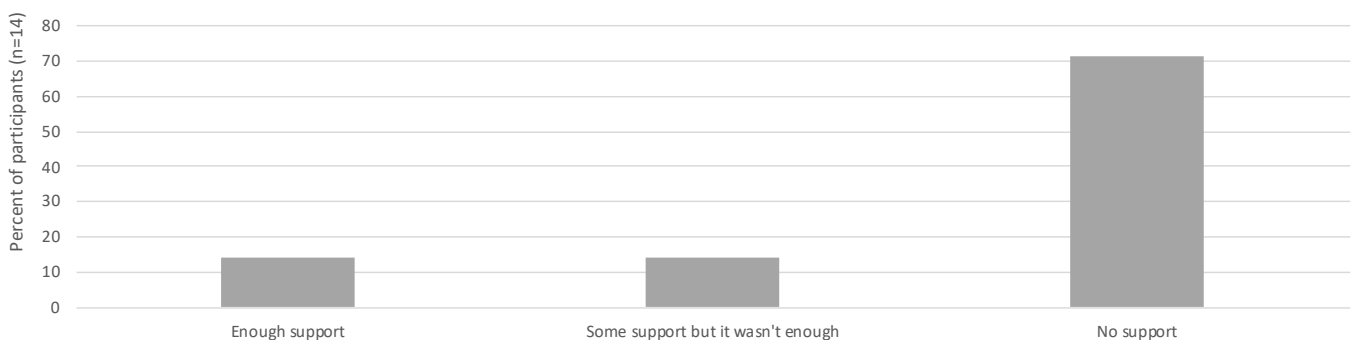


Figure 3.18: Information at diagnosis

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 7 participants (50.00%) who had no out of pocket expenses, and 5 participants (35.71%) who did not know or could not recall. There were 2 participants (14.29%) that spent between \$50 and \$150.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 5 participants (35.71%) the cost was slightly or not at all significant, and for 2 participants (14.29%), the burden of out-of-pocket expenses were moderately or extremely significant.

Table 3.24: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=14)	Percent
\$0	7	50.00
\$50 to 150	2	14.29
I'm not sure	5	35.71

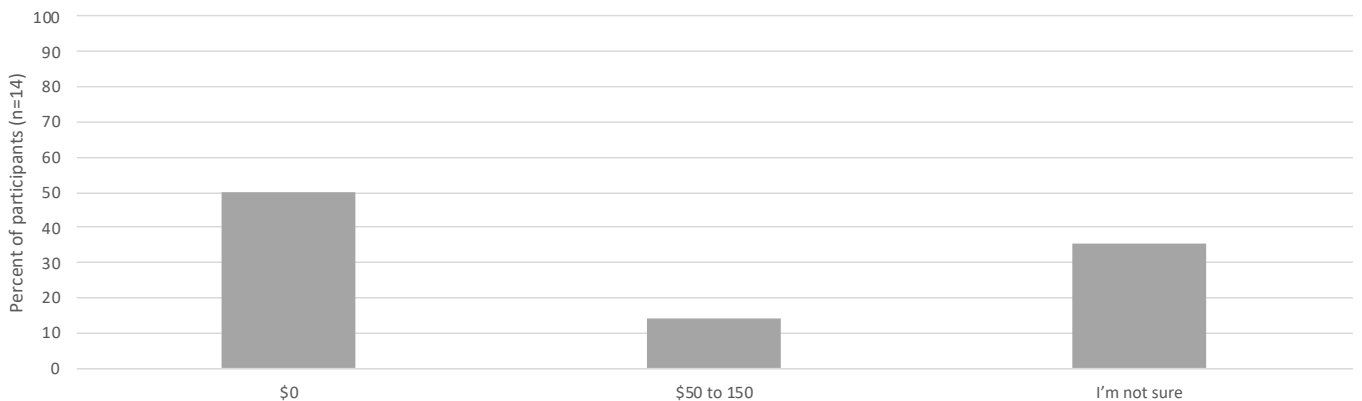


Figure 3.19: Out of pocket expenses at diagnosis

Table 3.25: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=14)	Percent
Not at all significant	3	21.43
Slightly significant	2	14.29
Somewhat significant	0	0.00
Moderately significant	1	7.14
Extremely significant	1	7.14

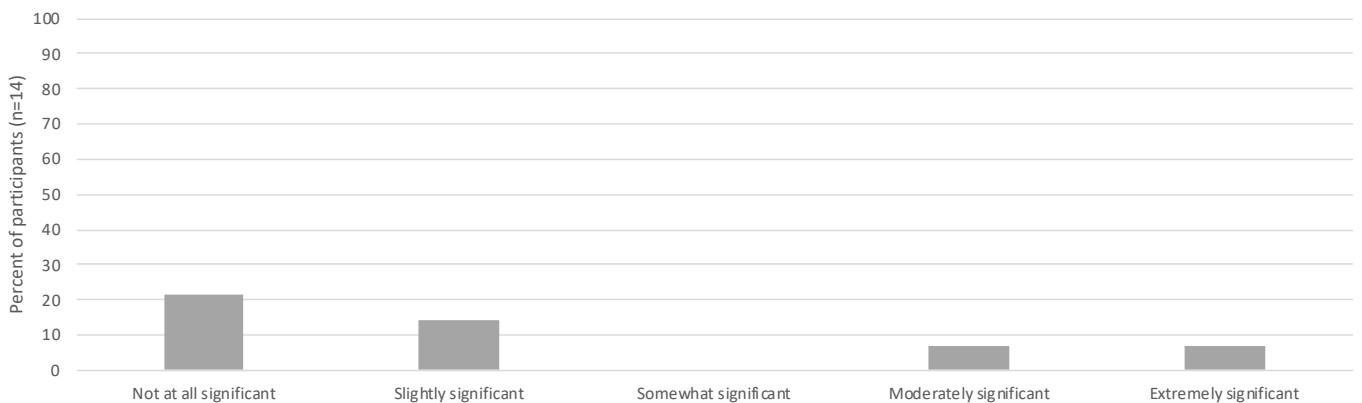


Figure 3.20: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did not have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=8, 57.14%). There was 1 participant (7.14%) who brought up the topic with their doctor, and 5 participants (35.71%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=5, 35.71%). There were 2 participants (14.29%) who did not have these tests and were not interested in them, and a total of 5 participants (35.71%) that had biomarker tests.

Table 3.26: Discussions about biomarkers

Discussions about biomarkers	Number (n=14)	Percent
Participant brought up the topic with doctor for discussion	1	7.14
Doctor brought up the topic with participant for discussion	5	35.71
Participant had no discussion about this type of test	8	57.14

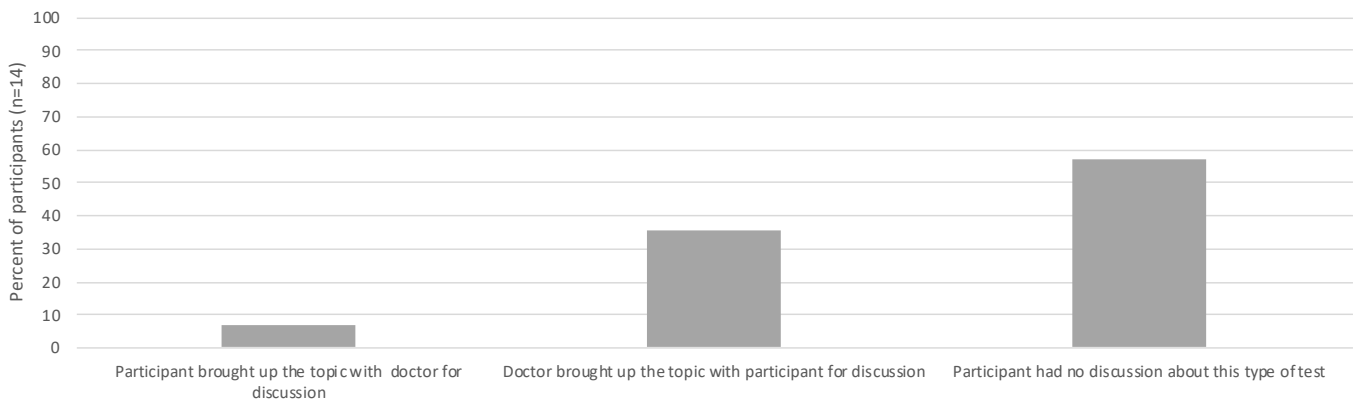


Figure 3.21: Discussions about biomarkers

Table 3.27: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=14)	Percent
Participant had this test and did not have to pay out of pocket for it	2	14.29
Participant had this test through a clinical trial	2	14.29
Participant had this type of test and paid for it	3	21.43
Participant did not have this test and is not interested in it	2	14.29
Participant did not have this test but would like to	5	35.71

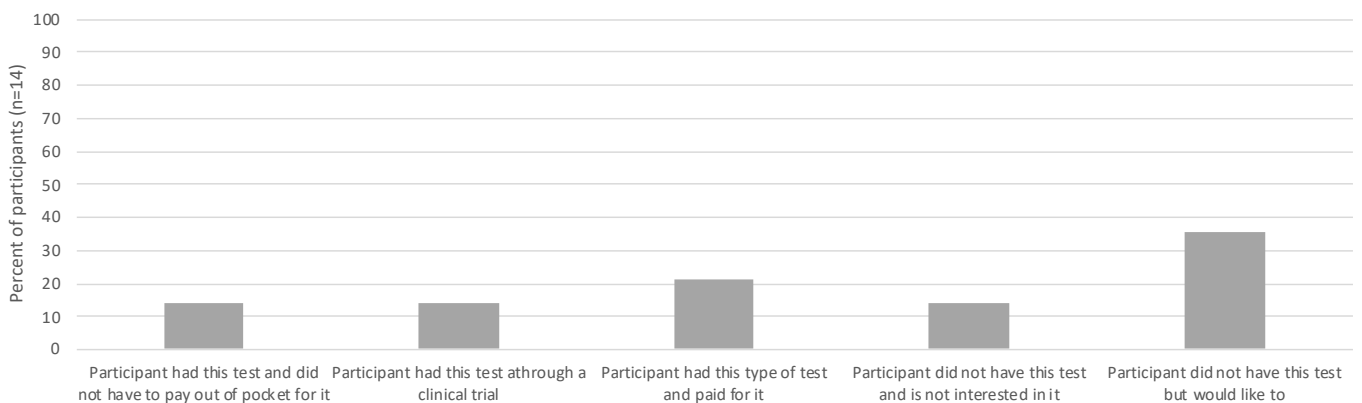


Figure 3.22: Experience of genetic tests and biomarkers

Current surveillance

Offered liver checks every 6 months

Participants were asked in the online questionnaire if they were offered liver checks at least every 6 months.

The majority of participants were offered liver checks every 6 months (n=9, 64.29%)

Table 3.29: Offered liver checks every 6 months

Offered liver checks every 6 months	Number (n=14)	Percent
No	5	35.71
Yes	9	64.29



Figure 3.24: Offered liver checks every 6 months

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (25.00%), and that there was uncertainty around prognosis (25.00%). Other themes included that their prognosis was positive, that their condition is manageable (16.67%), that there was no evidence of disease or that they are in remission (16.67%), that they were monitoring their condition until there is an exacerbation or progression (16.67%), that it being currently controlled (8.33%), and in relation to the risk of liver cancer (8.33%).

Participant describes prognosis in relation to uncertainty around prognosis

Nothing. After getting my blood testing results, the GP prescribed me the medication to treat.
Participant 005_2023AUHDV

No, that, that. No, my doctor did not tell me anything... so every time when I do blood test and everything. Nothing. Completely nothing. Yeah, nothing. Nothing at all.
Participant 001_2023AUHDV

Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression

Yeah, just keep going. Basically I get reviewed every six months with my 3 specialists and it's a case of they usually just see me.
Participant 007_2023AUHDV

Yeah. So I I've had, I've had treatment and that was actually quite a while ago...and that was prescribed to me for six months. So I took the six months of treatment. So there's been monitoring like I have, I have, I still get, I still get tests.
Participant 011_2023AUHDV

Participant describes prognosis in relation to it being currently controlled

Well, I had the treatment and haven't needed more.
Participant 010_2023AUHDV

Participant describes prognosis in relation to the risk of liver cancer

So I'm currently being medicated and from personal experience I have seen liver disease turns into liver cancer...so it's a very real and lived kind of experience. So the prognosis I know can be either way, depending on how your body reacts and what happens next really.
Participant 004_2023AUHDV

Table 3.30: Understanding of prognosis

Understanding of prognosis	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	3	25.00	2	33.33	1	16.67	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes prognosis in relation to uncertainty around prognosis	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes prognosis in a positive way, that their condition is manageable	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes prognosis in relation to it being currently controlled	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes prognosis in relation to the risk of liver cancer	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

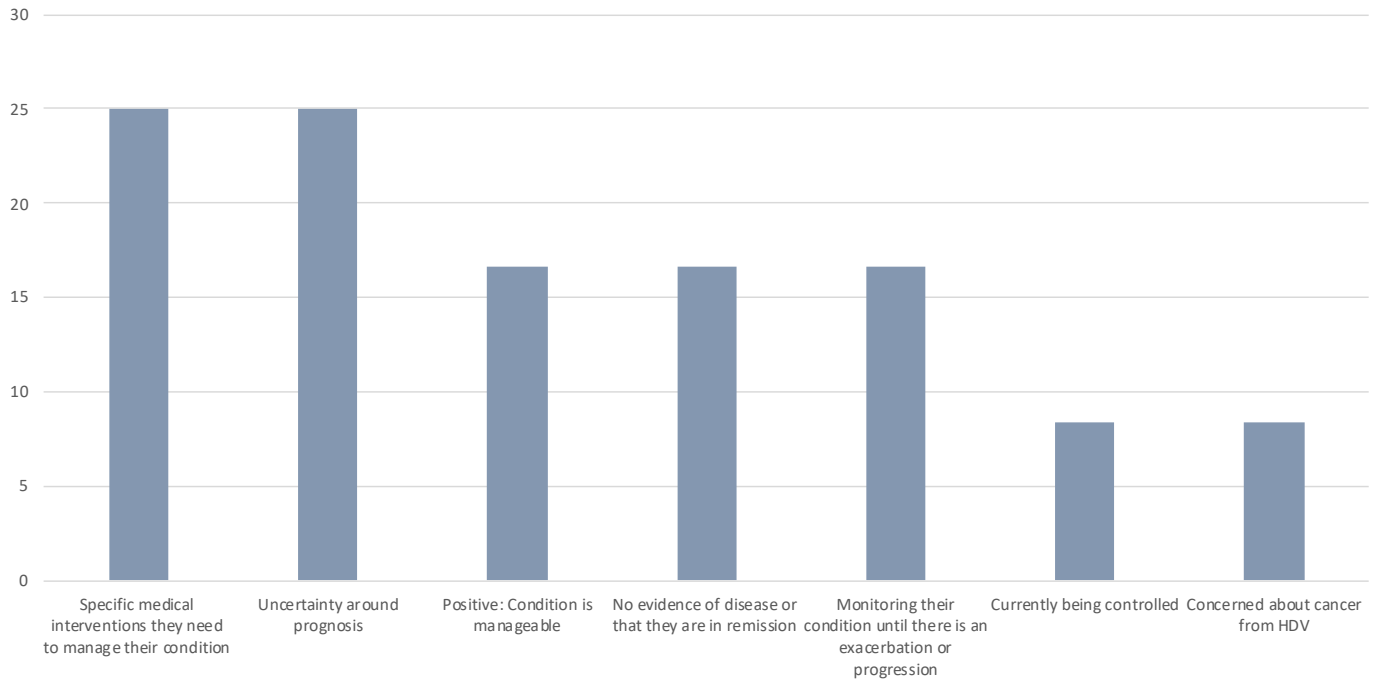


Figure 3.25: Understanding of prognosis