



Global Liver Institute **LIVER ADVOKIT™**

Advanced Advocacy Academy



www.globalliver.org



Global Liver Institute
LIVER ADVOKIT™

#A3experience



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About the Liver Advokit™

The Liver Advokit™ was created by Global Liver Institute as an advocacy companion for individuals within the liver community to build foundational knowledge and learn more about different avenues of patient advocacy. This comprehensive workbook supplements presentations held during the 2023 Advanced Advocacy Academy (A3) symposium with additional information and engaging activities. Our vision for this resource is to empower advocates like you to inspire positive change and make a lasting impact. We hope that by completing these activities you'll become more comfortable, confident and well-prepared to share your experiences to leaders throughout the liver community.

The History of Patient-Led Advocacy

Objectives

- Take inspiration from how present-day advocates are walking the road paved by their predecessors
- Identify your Rebel Health archetype
- Learn how to apply the Rebel Health Matrix to the challenges you face



In Susannah Fox's upcoming book, *Rebel Health: A Field Guide to the Patient-led Revolution in Medical Care*, she documents and names four **archetypes**: Seeker, Networker, Solver, and Champion.



This section is provided by **Susannah Fox.**

Health and Technology Strategist

Author, *Rebel Health: A Field Guide to the Patient-led Revolution in Medical Care*, Former Chief Technology Officer, US Dept. of Health and Human Services

1. SEEKER

Seekers sense that something is not right with their health and decide to take action. Maybe a diagnosis has dropped them into a maze filled with new terms and treatment options. Maybe their symptoms are mysterious, their worries are deep, and clinicians are not able to answer their questions. Seekers set to work, often hopeful but also often angry and frustrated. Seekers go on the hunt.

2. NETWORKER

Connection is an antidote to suffering and confusion. Networkers learn in community about their condition, cast off the burdens of isolation and shame, then urge each other to stand up for themselves. Networkers pick up signals and, if we tune in and listen, they can serve as an early warning system for crises—and solutions. Networkers pool resources.

3. SOLVER

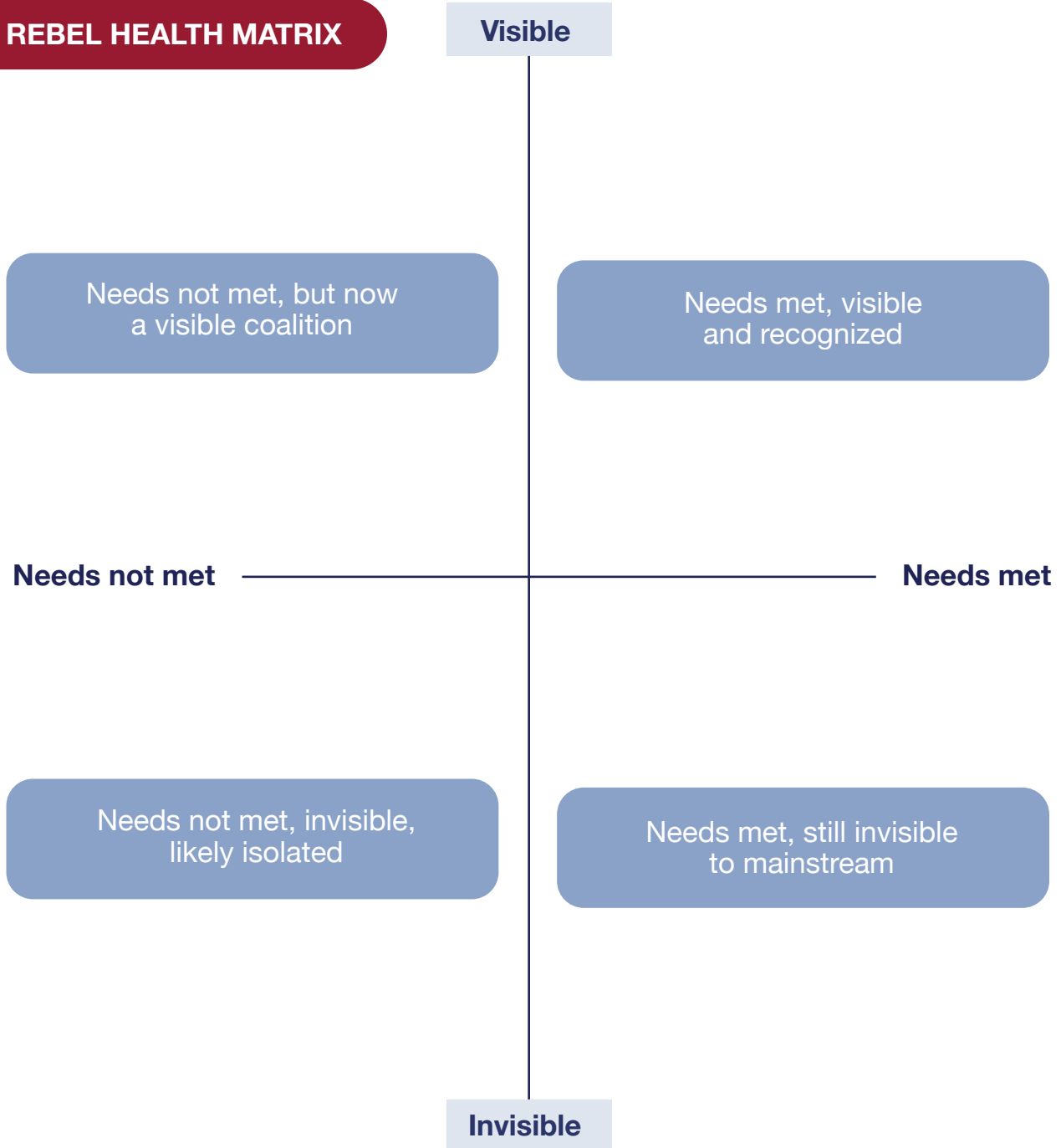
Solvers identify challenges, then test and develop new concepts, codes, and inventions to meet their needs. They creatively get access to what they need, bending and sometimes breaking rules in pursuit of a goal. Some Solvers openly share their designs online for other people to build on. Others keep their cards close to their vests, working inside regulatory and corporate structures. Solvers attack problems.

4. CHAMPION

Champions help take scrappy new ideas to scale. They give Seekers, Networkers, and Solvers access to resources held by mainstream institutions such as funding, media attention, regulatory guidance, or access to labs and manufacturing facilities. They make connections and see opportunities that others miss. Champions fast-track innovations.

Note: People can switch and combine these roles depending on the situation.

REBEL HEALTH MATRIX



Different rebel health archetypes shine in different situations. For example, in the lower-right quadrant – where a small group may have invented or found a solution, but mainstream health care does not even seem to acknowledge a problem’s existence – you need to become or recruit Networkers. By contrast, if you are in the upper-left quadrant, where a problem is well-known, you need to become or recruit Solvers.

ACTIVITY: Applying the Rebel Health Matrix to You

Which kind of rebel are you?	1. _____ 2. _____ 3. _____
Which kind of rebel do you need to add to your team?	1. _____ 2. _____ 3. _____
Think of a challenge you currently face. Where would you place it on the Rebel Health Matrix?	
Which kinds of rebels will be most helpful in solving the problem?	

Liver Literacy

Learning Objectives

Types of Liver Disease

Liver Function Testing

- Gain a better understanding of liver diseases
- Learn how to effectively communicate your needs and concerns as a patient to your care team
- Become confident and comfortable in leading conversations with your healthcare team

There may be people in your community or policymakers who have little knowledge about the liver. Often, liver patients are asked questions regarding their experiences, so it's very valuable to understand the basics of each category of liver disease as well as some of their common experiences.

Why should you care about liver health?

When you think about your health and vital organs, you probably think about your heart, lungs, and brain. Oftentimes, the liver is overlooked – despite being the second largest organ in the body and performing over 500 important functions.¹

1.5 billion people currently live with chronic liver disease worldwide.² Knowing the types of liver diseases, their causes, and ways to prevent liver disease can help you keep your liver healthy.

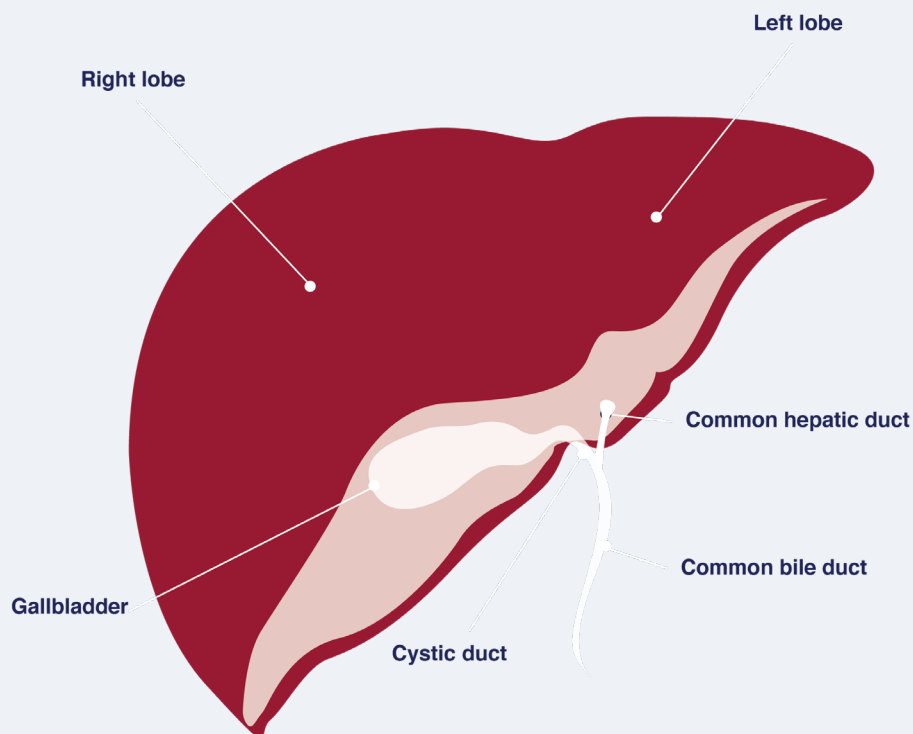
Through our combined advocacy efforts, patients and caregivers can work towards elevating the importance of recognizing liver health as a global public health priority.

What does the liver do?

The liver is an organ in your body about the size and color of a football. It's above the stomach. The liver has many jobs. It mainly filters your blood.¹

For example, it:

- helps prevent infections by removing bacteria from your blood
- removes sugar from your blood
- removes poisons and toxins from your blood
- produces a liquid called bile that breaks down fats in the food you eat
- helps your blood clot to form scabs when you are bleeding



With all these functions to accomplish, it's easy to see why the liver is so important to the body in helping us maintain good health and overall well-being.

What is liver disease?

Liver disease is any condition that damages the liver and/or prevents it from accomplishing the previously listed functions.

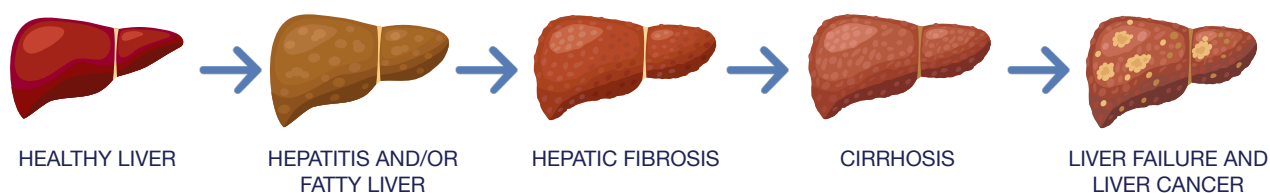
Symptoms of Liver Disease

When the liver is damaged, it can begin to function poorly. Sometimes this does not cause pain or problems that you would notice. Other times, you might:

- Develop yellow skin and eyes, called jaundice
- Have itchy skin
- Feel tired all the time
- Feel sick to your stomach, lose the desire to eat, or throw up
- Notice darker urine than usual
- Have pale, lighter-than-usual stool (poop)
- Notice swelling in your legs or ankles



These are some of the symptoms that may develop as your liver is damaged. As liver damage progresses, more serious and potentially life threatening conditions can occur.



How do you know if you have a liver disease?

There are many tests to figure out if you have a liver condition: blood tests, imaging tests (like an MRI or ultrasound), or, in certain instances, a procedure to take a tiny piece of the liver, called a biopsy.

What causes liver disease?

There are several different things that can cause liver disease, including infection, genetics, and lifestyle.

You can develop a liver problem at any age. Factors that contribute to liver disease include: physical inactivity, unhealthy diet, alcohol consumption, genetic disorder, autoimmune disorder, infection response to medication, and progression of a different liver disease.

How can you prevent liver disease, and what can you do to improve your liver health?

Fortunately, liver disease can often be prevented. Here are 7 things you can do to improve your health:

Stay up to date with your annual physical and vaccinations.

Many liver infections can be prevented with vaccines, and you can ask your doctor to run liver tests with other blood work or other additional screening.

Eat healthy and read nutrition labels.

Look for hidden fat, sugar, and sodium. Avoid fast food, processed food (in boxes and cans), and saturated fats. Ask your healthcare provider about the Mediterranean diet.

Stay active.

It doesn't have to be hard: Even 30 minutes of walking each day can help.

Drink fewer sugary drinks and more plain coffee and tea.

Avoid drinks that are high in sugar. Plain coffee or tea, though, can improve your liver health.

Maintain a healthy weight.

Ask your healthcare team about what a healthy weight goal looks like for you and what the best ways are to reach it.

Get enough sleep.

This is one of the best things for your health. Liver disease has been tied to poor sleep.

Drink less alcohol and more water.¹

Your liver has to work hard to process alcohol, and too much can damage it. The CDC recommends moderate consumption: 2 drinks or less per day for men and 1 drink or less per day for women.³ Plus, when you are hydrated, it is easier for your liver to filter blood.

What are the different types of liver disease?

There are over 100 different liver conditions.⁴ The most common diseases include:

Fatty Liver Disease

Nonalcoholic fatty liver disease (NAFLD) occurs when fat accumulates in the liver. Left untreated, NAFLD can progress to nonalcoholic steatohepatitis (NASH), which happens when too much accumulation of fat causes damage to the liver cells.

FATTY LIVER DISEASE	HOW DO YOU DEVELOP THIS TYPE?	CAN YOU TREAT OR MANAGE THIS TYPE?
NAFLD	Genetics, poor diet, high cholesterol, high blood pressure, and metabolic disorders (such as type 2 diabetes and obesity) ⁵	Weight loss, (7-10% of total weight) ⁵ healthy nutrition, and addressing underlying conditions like diabetes or high blood pressure can help.
NASH	Genetics, poor diet, high cholesterol, high blood pressure, and metabolic disorders (such as type 2 diabetes and obesity) ⁵	In addition to the above options, there is currently one medical device approved in the U.S. to treat NASH.

Alcohol-Associated Liver Disease

- Alcohol-associated liver disease occurs due to excessive use of alcohol. When the liver is unable to break down and process alcohol due to excessive drinking, it becomes damaged.⁶
- Alcohol-associated cirrhosis is linked to long-term alcohol abuse.
- To reduce further damage to your liver and to allow it to recover, the main treatment is to stop drinking altogether.

Viral Hepatitis

Viral hepatitis is an infection that causes liver inflammation and damage. There are five main types of viral hepatitis:

	HOW DO YOU USUALLY CATCH THIS TYPE?	HOW DO YOU PREVENT THIS TYPE?	HOW DO YOU TREAT THIS TYPE?
A	Contaminated food or water ⁷	Good hand hygiene, especially hand washing	A hepatitis A infection most often only requires minimal and supportive clinical care. ⁸
B	Contact with infected blood and other body fluids, such as sharing needles or unprotected sex ⁷	Hepatitis B vaccine, condom use, and not sharing needles, razors, etc	Antiviral therapy for hepatitis B is recommended to decrease complications. ⁹
C	Contact with infected blood ⁷	Hygiene with sharp object and blood	For most hepatitis C cases, antiviral treatment is recommended. Medications to manage ¹⁰
D	Requires hepatitis B infection, contact with infected blood and other body fluids, such as sharing needles or unprotected sex ⁷	Hepatitis B vaccine, condom use, and not sharing needles, razors, etc	hepatitis D symptoms are available. Treatment strategies to fight the infection are being evaluated. ¹¹
E	Contaminated food or water ⁷	Good hand hygiene, especially hand washing	Hepatitis E infection usually does not require antiviral medication. ¹²

In addition to the above treatment options, be sure to talk to your doctor for care guidance.

Rare Liver Diseases

Most of the over 100 liver diseases are rare. Usually they are either genetic (inherited) or auto-immune, and are often overshadowed by the more common diseases.

Some rare liver diseases include alpha-1 antitrypsin deficiency, Alagille syndrome, autoimmune hepatitis (AIH), biliary atresia (BA), progressive familial intrahepatic cholestasis (PFIC), primary biliary cholangitis (PBC), and primary sclerosing cholangitis (PSC).

Many rare liver diseases continue to lack treatment options but can be managed effectively.

Cirrhosis

Cirrhosis is end-stage liver disease. It is the severe scarring of liver tissue that can occur due to any liver damage. Managing and treating liver disease is crucial to reduce the likelihood of developing cirrhosis.

Cirrhosis usually cannot be cured, but its symptoms and complications can be managed. The condition could be prevented from getting worse. Managing the condition involves avoiding alcohol, losing weight, managing your nutrition, and taking medicine.¹³

Hepatic Encephalopathy

Hepatic encephalopathy (HE) is a nervous system condition that occurs when toxins build up in the blood due to the liver not working properly. These toxins travel to the brain and affect its function. HE is one of the most common issues that happens with cirrhosis and can cloud thinking and increase the risk of falling and tripping.¹⁴

HE treatments include medications to treat infections and to control bleeding, stopping the use of medications that can trigger an episode of HE, and any appropriate therapy for kidney issues.¹⁴

Liver Cancer

- Cancer that starts in the cells of the liver is called primary liver cancer.¹⁵
- The most common type of liver cancer is hepatocellular carcinoma (HCC), although there are other types.
- Liver cancer is the third deadliest cancer in the world.
- All liver disease can progress to liver cancer.
- Most liver cancer cases can be prevented by increased uptake of hepatitis B vaccinations, hepatitis C cures, and lifestyle management.¹⁶
- Treatment can involve surgery, localized treatments, artery injections, radiation, systemic therapy, or targeted drug therapy.¹⁷
- Every person is different, and working with a treatment team to make a personalized plan based

If one of these diseases reaches a late stage, you might need a liver transplant.



What is a liver transplant?

A liver transplant happens when your diseased liver is replaced with a healthy one. Unlike other parts of the body, the liver can regenerate on its own. This means that a liver transplant can come from either a donor who is still alive or a deceased donor. If you need a liver transplant, you are put on a waitlist for an organ. The liver transplant wait list priority is determined by something called a Model for End-Stage Liver Disease (MELD) score. A MELD score helps determine how soon you might receive your new liver.

Liver Function Tests: What are they?

Factors to Consider when Choosing a Clinical Trial

Liver function tests are blood tests used to help diagnose and monitor liver disease or damage. These different blood tests are used to find the amount of fat or damage in the liver. Specific blood tests include (but are not limited to):

Alanine Aminotransferase (ALT) Albumin
Globulins
Aspartate Aminotransferase (AST)
Blood Urea Nitrogen (BUN)
Glomerular Filtration Rate (GFR)
Alkaline Phosphatase (ALP)
Bilirubin
Hemoglobin A1c (HbA1c)
Platelet Ratio Index (APRI)
Gamma-glutamyltransferase (GGT)
L-lactate Dehydrogenase (LD)



Since liver disease is often hard to see, getting the lab tests and screening are important. Non-invasive tools can be safer and can even be more precise.

Liver tests only give us a snapshot of what is going on inside of your body; they do not always provide the full picture. The results of one lab test may not always cause concern, so care providers tend to look for trends of abnormal lab results. Feeling sick or stressed can affect your lab results, so pay attention to how your body feels.

How to Prepare for My Lab Tests:

1. Hydration is key. Make sure to drink plenty of water, starting two days before your lab tests!
2. Dress comfortably (opt to wear a short-sleeved shirt to make the process easier).
3. Ask your lab technician if you have any concerns about your lab tests. **Reference ranges can differ with age, sex, race/ethnicity, and even by lab, so make sure to communicate with your lab technician!**
4. Follow all instructions provided by your healthcare provider.

My blood work was just completed. What's next?

It is important to know when to expect your results. Interpreting results and sharing them with you can take hours, days, or weeks. The doctor's office may or may not reach out to you if your results are normal or within range. If results are normal, they can usually be delivered via a secure message through a mobile app, phone call, text, or letter.

Please consult with your doctor if your lab results seem to be out of range or abnormal. Make sure to write down any questions or concerns you may have to ask your care provider.

Frequency of Testing

Liver function tests monitor key proteins and enzymes that indicate whether the liver is functioning properly. Whenever you experience abnormal symptoms, are concerned about conditions that may cause liver dysfunction, or are taking medications that could damage your liver, you should have your liver function checked.

Liver function tests are generally recommended by healthcare providers when symptoms indicative of liver disease occur.

Symptoms to watch for:

- Jaundice (yellowing of skin or eyes)
- Diarrhea
- Dark-colored urine
- Light-colored stool
- Fatigue
- Abdominal pain
- Nausea and vomiting



In addition to these symptoms, liver function tests are recommended if you are at high risk for liver disease (e.g. certain medication use, family history of liver disease, etc.). While there are no specific guidelines regarding the frequency or age of testing, communicate with your provider to determine the frequency of testing that is right for you.

****Remember to always talk with your healthcare team, ask questions and work together to determine the best care plan for you.**

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Activity: Mapping Your Way into a Confident Conversation

What are three positive experiences in your health journey?

1. _____
2. _____
3. _____

What are three areas within liver health or patient care that you hope to improve through your sharing your experiences?

1. _____
2. _____
3. _____

Does your care center have opportunities for patients to be involved? (ie. patient advisory board) If so, who can I reach out to in order to get involved?

As you think about your journey with liver health, what are some experiences that stand out to you within these different stages of your journey? Do not worry if you have not experienced each of these steps yet. We want this exercise to help you understand your journey and help find key experiences to highlight.

Pre-Diagnosis	1. _____ 2. _____ 3. _____
Diagnosis	1. _____ 2. _____ 3. _____
Treatment	
Lifelong Care Management	

My Liver Health Journey:

NAME _____

DATE _____

DIAGNOSIS _____

DATE OF DIAGNOSIS _____

HEALTHCARE PROVIDER'S NAME _____

CONTACT INFORMATION _____



MEDICATION TRACKING

List all medications you are currently taking, including prescribed medications, over-the-counter drugs, supplements, and herbal remedies. Include the dosage and frequency of each medication.

Medication Name	Dosage	Frequency	Purpose

SYMPTOM TRACKING

Symptoms	Frequency	What improved/worsened it?

Ask Your Provider

Sometimes appointments can feel overwhelming and it can be difficult to recall everything on the spot. What sort of questions can you come prepared with to help you lead an effective conversation with your provider(s)?

Use this space to write down any questions or concerns you have about your liver health or treatment plan. Bring these questions to your next healthcare appointment for discussion.

Specialist/Provider	Question
Primary Care Provider	Sample Questions:
	<ul style="list-style-type: none">• How often should I be coming in for my lab work?• My lab tests are out of range, what do I do?• Are my current lab results concerning?• If so, what can I do to manage this?• Should I get repeat labs or why do I need repeat labs?• Will my tests be affected by diet or medications?• How do other health conditions affect my liver labs?• If my results are normal, does that mean I have nothing to worry about?• Are there any lifestyle changes or dietary modifications recommended for your liver health?

Media & Storytelling

Learning Objectives

- Learn how to use your story to effectively inspire and motivate your audience
- Learn how to headline your story/ give an elevator pitch
- Understand the nuances and differences between media platforms to most successfully deliver and tell your story

Stories are a persuasive form of communication that can influence audiences' emotions and beliefs. You can tell your story to share a lesson, provide an example of a widespread issue, or persuade someone that something is important.

Why do we tell our stories?

Facts and figures are important to making a point, but stories change hearts, minds, and actions. While there are many important parts of a good argument, the story usually stays with the audience longer than any other component. Regardless of whether you're talking to an elected official or your next-door neighbor, a story helps the audience to truly and thoroughly experience the ideas, thoughts, and emotions that you have experienced. Stories are essential to showing people how actions and policies can directly affect real people in the real world. Remember, you are the expert of your own story.

What are the goals of storytelling for advocacy?

- Building trust and connections
- Informing
- Educating
- Persuading



Why is storytelling effective in advocacy?

STORIES BUILD TRUST.

By sharing a bit of your own life, you can share the highs and lows and the emotions that you have experienced and take your audience on the journey with you. It is a reminder of your shared humanity, no matter how contentious or high-stakes the conversation might be otherwise.

STORIES HELP EVERYONE LEARN.

Whether through bedtime stories, parables, or even TV shows and movies, many of the lessons we learn about the world or about morality come through stories. Stories can help put overwhelming statistics or big trends into context – what does a certain pattern or obstacle actually mean for a person or family? Because of this, it is important to remember to not only focus on yourself, but also include other “characters” that your audience might relate to.

STORIES ARE MEMORABLE.

Especially when you evoke strong feelings, whether through a particularly emotional moment, tough decision, or miraculous twist in your story, your audience is likely to remember the story – and you – and your cause.

STORIES ENCOURAGE ACTION – WITHOUT TELLING PEOPLE WHAT TO DO.

While people do want to be informed as they make their decisions, most people do not enjoy being outright told what to do. Stories can make it clear to an audience that something needs to happen and might suggest what things did or did not work in your case, without demanding a very specific choice from a person. Often suggestions instead of demands can be much more effective – and the most persuasive ideas are usually those that the audience comes up with themselves!

STORIES ARE PERSUASIVE.

After traveling through the journey of your story with you, your audience has hopefully begun to empathize and recognize the issues that you have identified and are thinking of ways to get involved or assist in addressing these issues.

Elements of an effective advocacy story:

What are the goals of storytelling for advocacy?

1. Be authentic

Be yourself: You are the owner of your story. Speak from your heart.

2. Be relatable

Focus on the personal parts of your story and identify one or two specific details that your audience will relate with and remember. Use attention grabbing statements/hooks to keep the audience engaged with your story.

3. Be specific & data-driven

Focus on key messages that are aligned with your goals and others around you. The listeners or advocates will connect those key messages to moments in their own story as a means of demonstrating the message's power and importance.

4. Be concise

Make sure your story is clear, concise, consistent, and compelling. Your time as a person – and as a patient – has no doubt been long and complicated, but choose to share the pieces necessary to understand the specific story you want to tell. Save other details for another time when you're telling a story about a different topic.

5. Include a call to action

This is the most important part – and the part that distinguishes a story as one for advocacy! Before you end, make sure your listener understands the purpose of why you are sharing your story. Effective advocacy stories focus on positive change: either the positive change advocates have experienced or the change they hope to create with the help of the audience (other advocates/policymakers/nonprofits...)

How can I communicate my story well?

KNOW YOUR AUDIENCE

It is important to tailor your story to the audience. What parts of your story will your audience already be familiar with? What words will they typically use – and which need explanation? This will be different for a group of doctors, the staffer for a Member of Congress, a neighborhood organization, or an agency like the FDA.

REACH OUT TO LOCAL MEDIA

Develop relationships with people in your local media and use those connections to tell your story on as many platforms as possible.

- Traditional media – journalists, TV stations, local radio
- New media – social media (see appendix C), podcasts, online shows

PRACTICE MAKES PERFECT

Prepare for interviews by anticipating questions, thoroughly developing your answers, and using the set-up the interview will take place in. Speak at a normal pace (don't forget to breathe!), make eye contact with your interviewer, and sit with proper posture.

WRITE IT OUT

Whether it be a blog post, opinion piece, media advisory, or letter to the editor, actually writing your story out can outline your overarching message while including smaller – but just as

Effective advocacy storytellers are practiced, so they can strike a balance between using their natural speaking style, being genuine, and being confident.

When and where should I use my story?

No matter when or where, any time you're interacting with another person could be an opportunity for a moment of advocacy. From a brief moment in line at the grocery store to a speech in front of thousands of people, your words can move hearts and change actions. You can share your story:

- With legislators
- During a media interview
- On social media
- With a friend/neighbor/stranger
- In a press release
- In a newsletter

Activity: Telling your story with a purpose

This exercise allows you to organize your thoughts and serves as guidance to help you headline your story and/or give an elevator pitch. Be sure your story answers the 5Ws (who, what, when, where why). Keep in mind that the first few minutes and last few minutes of every public speaking opportunity are the most important.

Start off by introducing yourself: (approximately 1 sentence)

Why are you telling your story?

What are the basics of your story? (2-3 sentences)

Include your diagnosis, describe who, what, when, where, and how

Tips: Write down the first few details that come to mind and then narrow it down. Be selective and concise.

What is the main message of your story?

What other details will you include in your story? How are GLI, your care team, mentors and other advocates, etc a part of your story? What is your relation to GLI?

(1-2 descriptive sentences that will keep the listener engaged and wanting to know more about your story)

What is the call to action? What message do you want to leave the listener with?

Clinical Research & Development

Learning Objectives

- Understand distinguishing elements of a patient-centered protocol or study program
- Understand the clinical trials process and identify and overcome common barriers to clinical trial enrollment and retention

Clinical research is a type of scientific investigation aimed at improving health outcomes. Research is conducted in many different formats ranging from short online surveys to benchtop investigation to clinical trials involving thousands of people over the span of months.

What is a Clinical Trial?

- Clinical trials are research studies that test new medical treatments to improve health.
- The main goal is to find safe, effective ways to treat and prevent diseases, as well as improve participants' quality of life.
- They could involve testing a new drug or combination of drugs, medical device, or process, or even observing participants to look for trends and correlations.

Two Main Types of Clinical Trials

Interventional Trials Test new factors like drugs or education

Observational Trials Monitor participants' health over time

Benefits that clinical trials offer

- **Access to Emerging Treatments:** Some trials offer new options for conditions not responding to current treatments.
- **Improved Care:** Participants receive extra attention from the clinical team. Even patients in a placebo arm of a study tend to have better outcomes than usual.
- **Contributing for Future Patients:** Trials help develop new technologies and treatments.
- **Diverse Representation:** Studies need participants from different backgrounds to understand how treatments affect all people.

Factors to Consider when Choosing a Clinical Trial

DIVERSE REPRESENTATION:

- Studies need participants from different backgrounds to understand how treatments affect all people.

ELIGIBILITY

- Check with your doctor about available trials for you.

TRIAL ACTIVITIES

- Consider the time and effort needed for study activities like surveys or biopsies.
Activities may include: fasting, lifestyle changes, blood work, imaging tests, biopsies, and more

Common Terms within Clinical Trials include

PRECLINICAL STUDIES

otherwise known as bench or lab research, these studies assess feasibility and safety before human trials

RANDOMIZED CONTROLLED TRIALS

scientific experiments used in research, especially in medicine and social sciences, to assess the effectiveness of treatments or interventions

Steps may include:

- Design and protocol development
- Participants must be selected based on whether or not they are eligible for the study.
- Participants may be randomly assigned into either a treatment group or a control group.
- In blind studies, neither the participants nor the researchers know who is receiving the treatment and who is receiving the placebo, adding an extra layer of objectivity to the results.
- Data collection occurs at regular intervals to track participants' progress and document any changes in their health.
- Within data interpretation and reporting researchers provided compelling insights into the treatment's impact, paving the way for informed medical decisions and future studies.

PLACEBO GROUPS

- Some trials have control groups receiving standard care.
- Placebo effect refers to the phenomenon where a person experiences improvements in their health or symptoms due to their belief in a treatment, even if the treatment itself has no therapeutic value

ADVERSE EVENT

refers to negative or harmful outcomes that occur in participants who receive a particular treatment or intervention being studied

ELIGIBILITY

refers to the criteria that individuals must meet in order to be considered suitable candidates for participating in the study

Four Phases of Clinical Trials

- **Phase I:**
Investigate safety and best delivery of a new treatment in the human body
 - **Phase II**
Evaluate treatment whether the treatment works under ideal conditions
 - **Phase III**
Compare health results for the new treatment with the current standard of care
 - **Phase IV**
Monitor long-term effectiveness and side effects after approval in large, diverse cohorts of the population
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Barriers to Access

There are many obstacles to participation in clinical trials. Several relate to socioeconomic factors, culture, lifestyle, health, race, gender, and more:

- Health insurance
- Housing
- Transportation
- Citizenship
- Pre-existing health conditions
- Family obligations
- Work schedule



Finding Clinical Trials

Talk to your hepatologist or primary care physician, especially if you receive care at an academic center. They may know of or even be running trials for which you are eligible.

Search for trials online

EU	https://www.clinicaltrialsregister.eu/ctr-search/search
U.S.	https://clinicaltrials.gov/
International	https://www.who.int/clinical-trials-registry-platform

Informed Consent Process

It is absolutely essential that you, and other patients, completely understand the potential risk and benefits of enrolling in a clinical trial before agreeing to participate. The process of informed consent allows researchers to make sure this is the case. Informed consent can include pieces such as printed or digital recruitment materials, spoken instructions, Q&A sessions where you can ask for clarification, and more. You should always sign an informed consent document *before* enrolling in a study – and you are allowed to leave the study at any point, for any reason, if you decide to.

Make sure you know:

- How your data/information/results will be used
- That you may be exposed to risks and what those risks are
- What the experience will entail
- How the plan of research and the overall plan of the trial works
- What the potential risks are
- That participation is voluntary

This ensures that you make informed decisions on whether or not to participate.



Activity: Navigating Clinical Trials & Overcoming Barriers

WHO IS LEADING A CLINICAL TRIAL OR RESEARCH WITHIN YOUR GEOGRAPHIC AREA?

Can you identify organizations or clinical trial researchers in your community or hospital, care center, or academic centers that are actively leading research (in a disease area that is important to you)?

- 1.
- 2.
- 3.

The following are some barriers to participation in clinical trials that many people face. What potential solutions can you come up with for each barrier?

	BARRIER	SOLUTION
	You have heard about a new clinical trial for patients with the disease you were recently diagnosed with, but you don't know how to find out more or who to ask.	
	You experience language and cultural barriers during the explanation of a specific clinical trial.	
	You want to participate in a clinical trial but are concerned that you do not meet all of the study's inclusion criteria.	
	You do not fully understand the information included in the informed consent for a clinical trial you are considering participating in.	
	You have recently been diagnosed with liver cancer and do not understand the complexities of the disease or how to implement lifestyle changes to manage the disease and side effects.	
	You are a participant with difficulty getting to and from the clinic where your trial is located.	
	A trial you participated in has been completed and you do not know what to do to get information on study results.	
	You are experiencing difficulties managing the side effects of the clinical trial protocol.	

	What do you consider to be a barrier to access and what are some solutions that you would provide?	
	What can GLI, your colleagues, and the liver community do to help you work through these barriers?	

Use this space to write down any questions or concerns you have about your participation in research. Bring these questions to your appointment for discussion.

SAMPLE QUESTIONS

- *How do the possible risks, side effects, and benefits of this trial compare with those of my current treatment?*
- *What tests and procedures would I undergo?*
- *How long will the study last?*
- *If I benefit from the intervention, can I continue receiving it after the trial ends?*
- *Who will oversee my medical care during the trial?*
- *Where do I have to go to participate in this trial?*
- *Is there travel involved?*

Navigating Healthcare & Coverage

Learning Objective

- Learn the basics of healthcare coverage, enrollment, and informed decision-making
- Explore different healthcare systems to find the one that suits you best
- Discover how healthcare is evolving to prioritize quality and affordability
- Understand how healthcare teams work together to provide comprehensive care

Healthcare is a fundamental aspect of our lives, impacting our well-being in countless ways. It's not just about treating illnesses; it's about ensuring you receive the right care, at the right time, from the right providers, and in the right way. Understanding how to navigate healthcare coverage is essential.

Steps to Obtaining and Maintaining Healthcare Coverage

The following steps will help you navigate the U.S. health insurance system.

1. Investigate Options

- Explore employer-sponsored plans, government programs (Medicaid, Medicare), and individual plans.
- Evaluate coverage details and costs based on your healthcare needs.

2. Check Eligibility

Government or state subsidized programs

- Visit HealthCare.gov (or your state's healthcare exchange website, if applicable) to apply online.
- Create an account or login if you already have one.
- Follow the prompts to determine your eligibility for government-subsidized plans (or Medicaid).
- Provide accurate information about your income, household and other relevant details
- Review if you are eligible and see which programs you qualify for.

Employer-sponsored insurance coverage

- Consider your employment type and status to see if you are eligible for an employer-sponsored plan.
 - Contact your employer's human resources or benefits department for guidance.
 - Verify if dependent coverage is allowed (if you have family members who you would like to be covered on your plan).
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-

3. Enroll in Coverage

- Enroll during open enrollment periods for most plans. This includes particular times of year for marketplace plans, at the moment you or your spouse or parent begins a new job, or for employer-sponsored plans, at the point of a Qualifying Life Event, including getting married, having a baby, or losing health coverage, which opens up a special enrollment period.

Complete applications with personal information and required documentation.

- Find help in your area by visiting healthcare.gov.
- Enter your ZIP code for a list of local people and organizations that can help you apply for coverage.
- Use a certified enrollment partner.
- Enroll over the phone.
- Fill out and mail in a paper application.

4. Understand Your Coverage

- Review policy details, benefits, deductibles, and limitations.
- Familiarize yourself with the provider network and in-network options.

5. Access and Use Coverage

- Use your insurance card to access medical services, doctor visits, and prescriptions.
- Submit claims for reimbursement if needed, following insurer guidelines.

6. Maintain Healthcare Coverage

- Premium payments (or premiums) are regular fees paid by policyholders to their insurance provider to continue insurance coverage and access to specified benefits and services.
- Pay monthly premiums to keep your coverage active.
- Failure to pay may lead to loss of coverage.

7. Schedule Regular Checkups and Care:

- Schedule and attend regular checkups and preventive care visits.
- Manage health and catch issues early for better outcomes.

8. Manage Costs:

- Understand copayments, deductibles, and coinsurance. (See Appendix D)
- Budget for potential healthcare expenses.

9. Update Information

- Keep coverage details updated for any life changes.
- Update for events like marriage, childbirth, or employment changes.

10. Review Annually

- Review coverage annually during open enrollment.
- Consider switching plans if your healthcare needs or budget have changed.

Who is involved in the healthcare delivery system?

Healthcare systems are complex due to numerous involved parties. Providing the right care to patients involves research, insurance, delivery, and payment. These processes are extensive, especially for third-party insurers. The cost of healthcare delivery is addressed by four main parts, and many players are involved in ensuring cost-effectiveness.

These players include

Funders

the source of the money to pay for care

Insurance providers

the entities that determine what health services will be paid for and how much will be paid

Care delivery

the clinics, community health centers, hospitals, nursing homes, diagnostic centers, and the doctors, nurses, and other staff who provide the care

Payment itself

which though often provided by insurance companies themselves, can also be paid out by a third-party claims processor

The entities responsible for each of these roles depends on the system of healthcare that you are in.

Common Models of Healthcare Insurance Systems

MODEL	DEFINITION	MAIN SOURCE OF FUNDING	INSURANCE PROVISION*	CARE DELIVERY	EXAMPLE
Bismarck Model (private payer)	Health insurance companies provide coverage to members who access care through employers or purchased plans. They pay a portion of medical costs at negotiated rates with hospitals, with patient contributions.	Employer and employee contributions (payroll deduction) or plans purchased directly from a marketplace (out of pocket)	Private insurance companies (for instance, Aetna, BlueCross BlueShield, Humana,	Clinicians are mostly private entities.	Germany; U.S. coverage through one's employer
National Health Insurance Model (single payer)	Government funds all insurance coverage, reimbursing private clinics and practitioners.	Taxes, sometimes copays	Government	Clinicians are mostly private entities.	Canada; U.S. Medicare system
Beveridge Model (government-run healthcare)	Everyone has government-provided, government-funded healthcare with minimal out-of-pocket costs for patients.	Taxes, sometimes copays	Government	Clinicians are government employees.	National Health Service in Great Britain; U.S. Veterans Affairs hospital system

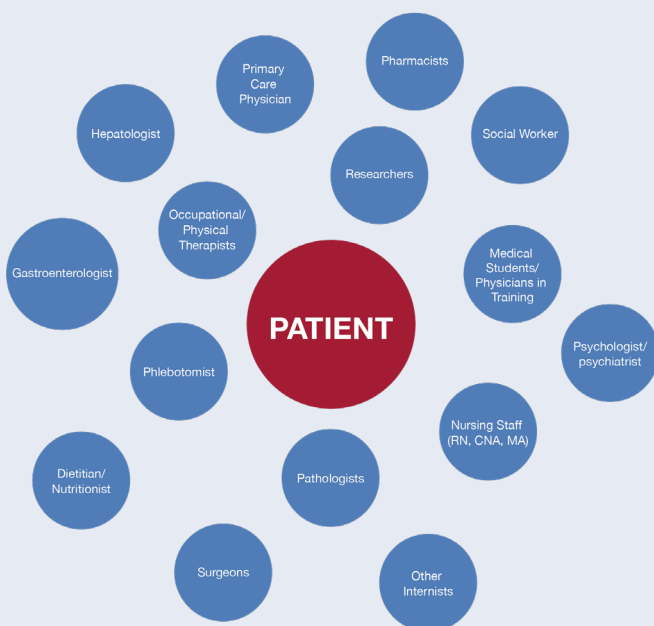
Uninsured Model (out-of-pocket payment)	Patients directly pay for medical costs using their own cash or credit.	Patients' cash and credit	N/A	Clinicians are mostly private, though not-for-profit care centers may exist as well.	Many low- and middle-income countries; U.S. uninsured
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* In some cases, payment may be processed by a third-party claims processor on behalf of a health insurer.

Universal healthcare is a term that comes up frequently when discussing a health insurance system. While it sounds like it might be its own model, universal healthcare, rather, is a goal that any model can achieve. It is simply a health system in which all people have access to the full range of health services, when they need them, where they need them, no matter who they are.

The Multidisciplinary Process

Your care will likely involve a number of different healthcare providers, all with different expertise and roles to play. When they collaborate to understand the full picture of your care and make decisions aligned with your health and goals, your healthcare experience can significantly improve.



Please note that the following list provides a general overview of healthcare practitioners who might interact with a liver patient, but this can vary, and it does not necessarily imply that all of them will be involved in the patient's care pathway.

Value-Based Healthcare

Value-based healthcare incentivizes outcomes for patients rather than the delivery of care itself. In other words, it links the amount of money that those who deliver care (clinics, hospitals, healthcare providers) receive to specific positive outcomes or episodes of care, rather than receiving a direct payment for each exam, test, or procedure that is completed (known as a “fee for service” model). This approach to healthcare encourages providers to use evidence-based, cost-effective options rather than treatments that might net the provider or system the most money. Areas of focus within value-based care include equity, quality and cost of care.

How might patients benefit from value-based care?

- Empowers patients with personalized, patient-centered treatments
- Ensures equitable access to high-quality care for everyone
- Focuses on preventive services and innovative treatments for better long-term health outcomes
- Drives positive changes in healthcare policies, accountability, and efficient resource use
- Strengthens patient-provider relationships and enhances overall healthcare satisfaction

Features of Patient-Centered Care

INDIVIDUALIZED FOCUS

tailor care for each patient’s unique needs, preferences, and values

SHARED DECISION-MAKING

collaborate with patients in healthcare decisions, respecting their autonomy

EFFECTIVE COMMUNICATION

emphasize clear and empathetic communication between providers and patients

OVERALL WELL-BEING

consider emotional, psychological, and social aspects of patients’ health

QUALITY OF LIFE

aim to improve overall well-being and enhance patients’ satisfaction and outcomes

100

Measures for Value

QUALITY-ADJUSTED LIFE YEARS (QALY)

This generic measure of disease burden and treatment quality tries to distill quality of life to a single number, by measuring “adjusted” years based on disease or disability.

EQUAL VALUE OF LIFE YEARS GAINED (evLYG)

This measure evenly measures any gains in lifetime, regardless of whether a treatment

This measure evenly measures any gains in lifetime, regardless of whether a treatment improves quality of life.

INCREMENTAL COST-EFFECTIVENESS RATIO (ICER)

This measure is calculated by dividing the difference in total costs by the difference in the

This measure is calculated by dividing the difference in total costs by the difference in the chosen measure of health outcome to determine how cost-effective each intervention is.

Who measures value in the US?

INSTITUTE FOR CLINICAL EFFECTIVENESS RESEARCH (ICER)

a nonprofit, non governmental institution that evaluates clinical and economic value of medical interventions, including drugs, devices, and diagnostics

NATIONAL HEALTH COUNCIL (NHC)

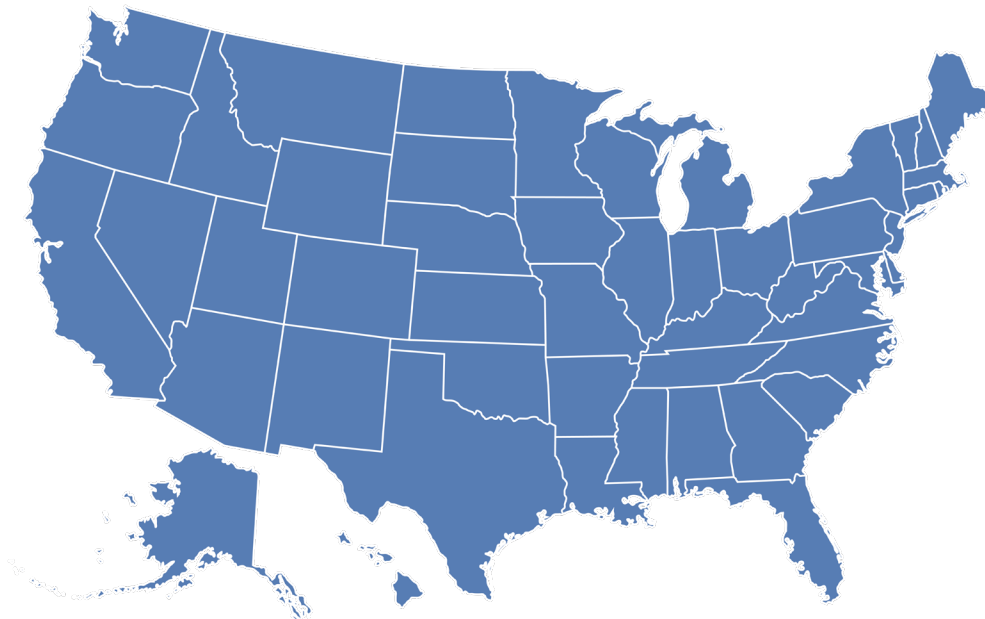
a nonprofit association that aims to improve patient-focused healthcare, interventions, and cost reduction through health and patient advocacy organizations

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)

US-based nonprofit that examines health outcomes and treatment effectiveness to help payers decide which therapies to cover

INNOVATION AND VALUE INITIATIVE (IVI)

a nonprofit membership organization that collaborates with thought leaders to discuss and define value in healthcare, seeking common ground among all stakeholders



Your health is your most valuable asset, and understanding how to protect it is a skill that can change your life for the better.

Activity: Exploring Your Healthcare Coverage and Care Experience

HEALTHCARE COVERAGE	
Who is your healthcare coverage provider?	
What are some barriers to you obtaining healthcare coverage?	
What are some barriers you've had when it comes to maintaining your insurance coverage or ensuring your healthcare services get covered?	

YOUR CARE TEAM	
Who is a part of your care team? Include each provider within your multidisciplinary team (if applicable).	
How has several members of your care team working together improved your experience and outcome (if applicable)?	

VALUE-BASED HEALTHCARE

What does value-based healthcare mean to you?

What are your specific barriers (if any) to receiving care?

PERSONAL REFLECTION

Reflect on your understanding of the healthcare system and the importance of creating value-based care.

How does this knowledge improve your healthcare decision-making process?

Understanding Policy & Meeting with Policymakers

Learning Objectives

- Understand the legislative process in the United States
- Understand how to engage policymakers on liver issues
- Identify major policy entities in the US and throughout the world
- Develop a plan of action that fits where you are at in your health advocacy journey



Who Makes Policies, and How?

	Executive	Legislative	Judicial
FEDERAL	President, Vice President, Cabinet, various departments & agencies	Senate & House of Representatives (collectively Congress)	Supreme Court, Federal Judicial Courts
STATE	Governor, Lieutenant Governor, & Cabinet	State Senate & State House (collectively State Legislature)	State Courts

The Legislative Process

In the United States, the legislative process can be broken down into five steps:

1. When a bill is written, bills originating in the House will be designated with “H.R.” and in the Senate will be designated with “S.,” given a bill number, and introduced in either the House or the Senate.
2. The Speaker of the House or presiding officer of the Senate assigns the bill to the committee that is in charge of the topic or issue related to the bill.
3. The committee meets and may review the bill, hold a public hearing on the bill, and make changes as needed. Then, it votes on whether to approve the bill and send it to other committees for review.
4. If the bill has support, it is placed on the calendar of either the House or Senate for debate and goes through budget approval with that chamber. If a bill requires more support to proceed, it is forwarded to the other legislative chamber (House or Senate) for consideration. This step is taken in the hope of gaining additional endorsements from legislators in the second chamber.
5. Once both chambers agree on the language of the bill, it goes to the President (or Governor at the state level) to be signed into law.



Know Your Legislators

Before meeting or speaking with any of your legislators, it is important to know some key information about them:

1. Political Party

Identify the political party they belong to



2. Tenure in Office

Learn how long they have been serving as legislators

3. Committee Assignment

Find out which specific committees they are part of

4. Issues of Concern

Understand the topics or causes they are passionate about

5. Past Legislation

Look into bills they have sponsored in the past

By studying these details and focusing on a specific bill, you can engage effectively with your legislators, committee chairs, and staff.

- U.S. House of Representatives: **<https://www.house.gov/>**
- U.S. Senate: **<https://www.senate.gov/>**
- Each state has a house and senate (except Nebraska, which is unicameral). Your state should have a website you can search to find your legislator.

Types of Congressional Resolutions

Resolutions express the opinion or will of a legislative body, but unlike bills, are limited to Congress or one of its chambers.

1. Joint Resolution

Requires agreement from both the Senate and the House, designated as “H.J.Res.” or “S.J.Res.” followed by a number; needs the President’s signature to become law

2. Concurrent Resolution

Affects both the House and the Senate, expressed to show the sentiments of Congress, designated as “H.Con.Res.” or “S.Con.Res.” followed by a number; not presented to the President for action

3. Simple Resolution

Addresses matters for only one house of Congress, designated as “H.Res” or “S.Res” followed by a number; does not require approval from the other house or the President and does not have the force of law

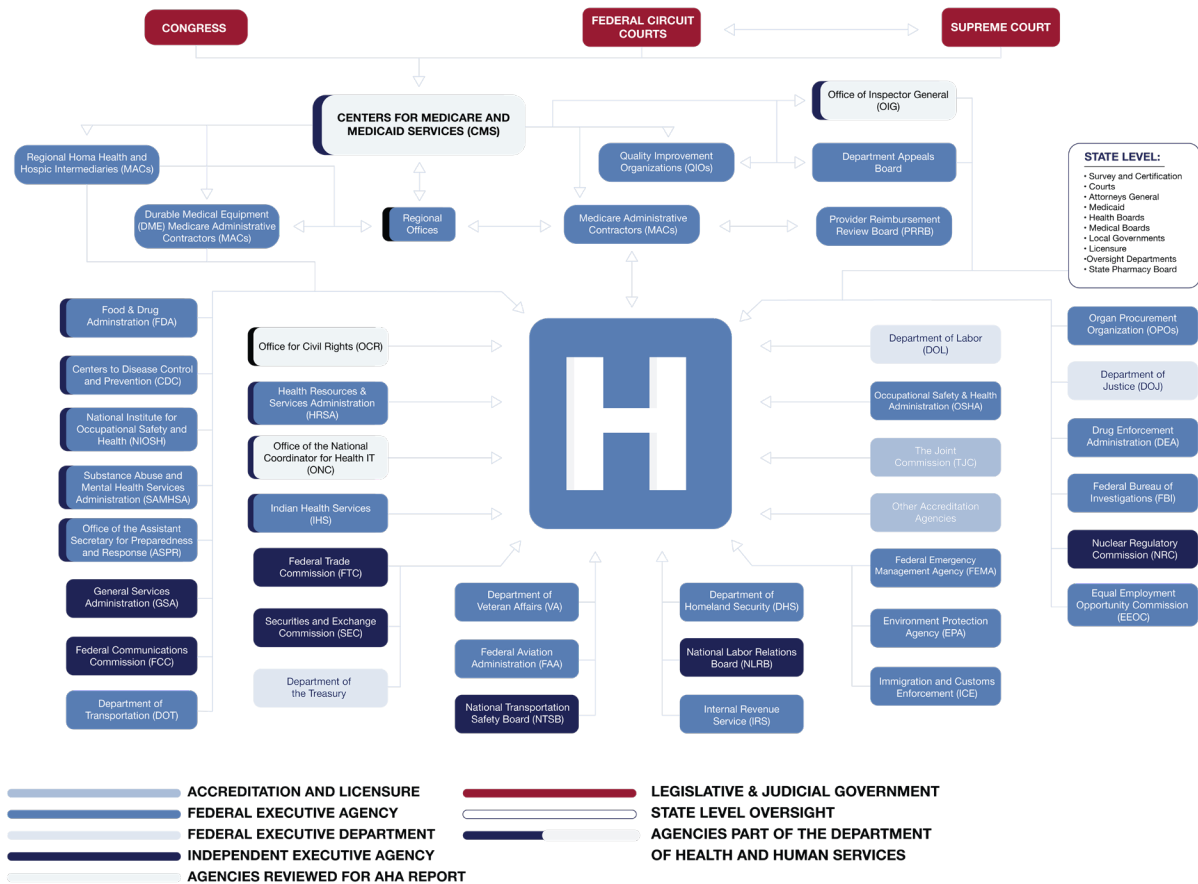
Federal and International Agencies

Legislation is just one part of the health policy life cycle. Agencies at the state, federal, and international levels then receive the laws, interpret them, and carry them out – a very important part of the policy process.

U.S. Agencies

The executive branch includes various departments and agencies responsible for implementing laws passed by the legislative branch. These agencies significantly influence hospital and healthcare systems, healthcare coverage, and the approval of new medical treatments, diagnostics, and devices.

Federal Agencies with Regulatory or Oversight Authority Impacting Hospitals



Based on a graphic from the American Hospital Association, 2017

U.S. Department of Health and Human Services (HHS)

Provides health services, research, and works with other agencies for public health;

The following agencies are part of HHS:

Centers for Disease Control & Prevention (CDC)

Protects the nation from diseases by conducting research and sharing health information. You can access educational resources and training on their website: <https://www.cdc.gov/>

National Institutes of Health (NIH)

Conducts medical research for longer and healthier lives. Find liver disease research and general science education on their website: <https://www.nih.gov/>

Centers for Medicare and Medicaid Services (CMS)

Provides information on Medicare and Medicaid, improves patient care, and makes healthcare affordable and accessible. Engage with CMS through outreach and education: <https://www.cms.gov/>

Office of Minority Health (OMH)

Works to eliminate health disparities among minority populations. Provides educational resources and grants to improve minority health: <https://www.minorityhealth.hhs.gov/>

Office of Disease Prevention and Health Promotion (ODPHD)

Creates programs and services to support public health objectives. Use their Health Literacy resources to educate others: <https://health.gov/our-work/national-health-initiatives/health-literacy>

Food and Drug Administration (FDA)

Ensures safety and efficacy of drugs, devices, and more. You can advocate for liver patients by participating in public advisory committees and other meetings. Learn more at: <https://www.fda.gov/>

Department of Veterans Affairs (VA)

Provides benefits and healthcare services to veterans. Their website has comprehensive liver disease information and educational resources: <https://www.va.gov/>

Department of Defense (DOD), Congressionally Directed Medical Research Programs (CDMRP)

Funds research in important medical areas. Advocates can apply for funding and become consumer reviewers. Learn more: <https://cdmrp.health.mil/>

US Department of Agriculture (USDA)

Provides guidance on agriculture, nutrition, and rural development. Works to ensure a thriving food system and preserve natural resources. Learn more: <https://www.usda.gov/>



International Agencies

WORLD HEALTH ORGANIZATION (WHO)

Promotes health worldwide, responds to emergencies, and provides health coverage. Use their fact sheets and research publications for education: <https://www.who.int/news-room/fact-sheets>

EUROPEAN CDC (ECDC)

Protects the European population from infectious diseases. Access resources and public health training through their Virtual Academy. Learn more: <https://www.ecdc.europa.eu/en>

EUROPEAN MEDICINES AGENCY (EMA)

Regulates medical research in Europe. Find information about medical advancements and participate in public hearings here: <https://www.ema.europa.eu/en>

UK NATIONAL HEALTH SERVICE (NHS)

Provides healthcare services in the United Kingdom. Visit their website: <https://www.nhs.uk>

ARGENTINA MINISTRO DE SALUD:

Administers healthcare and health research in Argentina. Visit their website: <https://www.argentina.gob.ar/salud>

AUSTRALIA AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH

Develops policies and programs to improve health in Australia. Visit their website: <https://www.health.gov.au>

BRAZIL MINISTÉRIO DA SAÚDE

Promotes health through campaigns and legislation in Brazil. Visit their website: <https://www.gov.br/saude/pt-br>

CANADA HEALTH CANADA (HC) AND PUBLIC HEALTH AGENCY OF CANADA (PHAC)

Improve health outcomes and protect Canadians against health threats. Learn more at: <https://www.canada.ca/en/health-canada.html> and <https://www.canada.ca/en/public-health.html>

CHINA NATIONAL HEALTH COMMISSION OF THE PEOPLE'S REPUBLIC OF CHINA

Improves health through various departments. Visit their website: <http://en.nhc.gov.cn>

INDIA MINISTRY OF HEALTH AND FAMILY WELFARE

Oversees health and research departments in India. Visit their website: <https://main.mohfw.gov.in>

JAPAN MINISTRY OF HEALTH, LABOUR, AND WELFARE

Manages health, labor, and welfare policies in Japan. Find more information at <https://www.mhlw.go.jp> or <https://www.mhlw.go.jp/english>

MEXICO MEXICO MINISTRY OF HEALTH (COFEPRIS)

Regulates health products and services in Mexico. Find information at <https://www.emergobyul.com/resources/mexico/cofepris>

NIGERIA FEDERAL MINISTRY OF HEALTH

Contributes to health services in Nigeria. Visit their website: <https://www.health.gov.ng>

SOUTH AFRICA NATIONAL DEPARTMENT OF HEALTH

Provides resources on health access and disease prevention in South Africa. Learn more at <http://www.health.gov.za>

If your country's health department was not listed, we recommend visiting the country's official webpage to locate health-specific information.

Avenues for Advocacy



1. Peer-to-Peer Advocacy

Start with people you know and trust. Talk to friends, family, and colleagues about liver health and why it matters to you. Consider meeting for coffee, sending texts/emails, or hosting an event in your home to raise awareness and gain support.

2. Grassroots Advocacy

Bring together the community's voices to support liver health. Use methods like petitions, letters of support, hill days, letter writing campaigns, and marches/walks to show decision-makers the widespread impact of the cause.

3. Social Media Advocacy

Leverage social media to reach a broader audience. Use your platforms to educate the public, interact with decision-makers, stay updated on the field, and share successes and updates related to liver health.

4. Traditional Media Advocacy

Utilize print, digital publications, and TV news to reach beyond your network. Create news through press releases and events, comment on relevant news stories, and media-train a spokesperson to represent the cause.

5. Legislative Advocacy

Meet with legislators to educate them about liver health and advocate for policies that promote it. Stay informed about legislators' positions and priorities, and show gratitude for their support.

6. Administrative Advocacy

After a bill becomes law, advocate during its implementation. Provide public comments, meet with decision-makers in relevant departments, and share data and personal insights to help shape the rules and ensure effective implementation of the law.

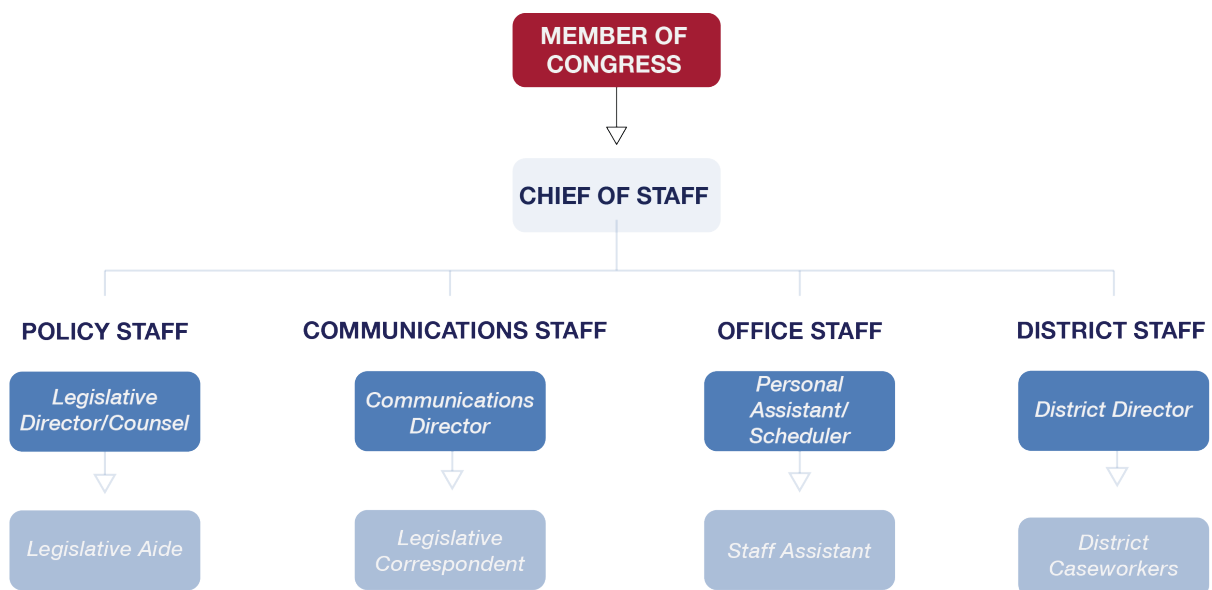
Preparing for Congressional Meetings

A few basics

- Be prepared to go through security – it could take an extra 10 minutes.
- There are underground tunnels between the House buildings and the Senate buildings.
- Stick to the topic at hand. Keep any other politics or opinions, especially contentious and distracting issues, out of your discussion.
- You're not expected to be an expert on legislation – some questions might require a follow-up. Don't hesitate to indicate that you'll be back in touch with them.

CONGRESSIONAL REPORTING STRUCTURES ARE HIERARCHIAL

Sample Organization of a Congressional Office

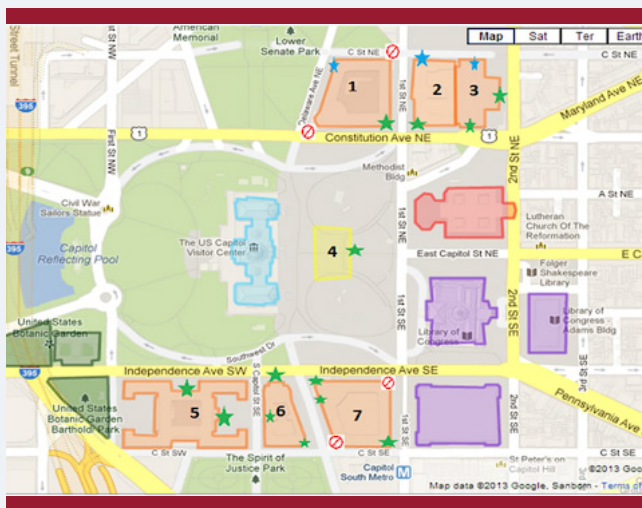


ANALYSIS

- Members of Congress are advised to structure their office into discrete areas, depending on their staffers' functions
- Nonetheless, almost every office will have a unique structure and series of staff duties
- The vast Congressional workload means that the day-to-day reporting structure of a Congressional staffer may look very different in practice than on paper

Who You Are Meeting With

- Most meetings on Capitol Hill will not include a Member of Congress.
- Legislative Directors and Legislative Assistants track the day-to-day policy developments in specific issue areas (ex. healthcare, labor, veterans, and defense policy).
- While some staff members may be well-versed on the issues we are presenting, others will have only a basic understanding.



Map provided by Thorn Run Partners, 2023

Where Will the Meetings Be

- Capitol Hill staff work in tight quarters, and meetings are often confined to a small meeting space.
- Typical meetings are held at a small table in a room full of other staff members who are working at their cubicles.
- Sometimes meetings are held in the reception area in the front of an office - and occasionally in the larger office of the Member of Congress.
- It is not unusual to conduct the meeting in the hallway.

General Meeting Tips

- Congressional offices care about serving their constituents; be sure to emphasize the presence you have in the district – do you live there? Is your care provider located there?
- Tell stories about how policies directly impact real liver patients.
- If you don't know an answer to a question, don't make it up. Saying you will follow up is always appropriate and gives you a good touchpoint to continue the conversation.

How Should You Follow Up

- Send a “thank you” email as soon as possible after meeting with Congressional staff.
- Put in writing any commitments that the staff made during the meeting.
- Answer any follow-up questions that you were unable to answer during the meeting.

Don't Forget: Take Photos!

- Encourage the Member or staffer you meet with to take a picture with you following the meeting so it can be posted to your account.
- Posting images as part of your post is a great social media practice for driving engagement on your account.
- You can also take a picture outside of their office next to the plaque on the wall.



Activity: Meeting with your Representative/ Congressional Office

Can you name your member(s) of Congress or your elected officials?	
What are the committees that they currently sit on? What are some of the issues they prioritize?	
Do you know how to contact them to schedule meetings?	

<p>Do you know where your congressional district office is located?</p>	
<p>Do you have a way to contact their office? Phone number?</p>	
<p>Brainstorm how to build relationships with these officials.</p> <ul style="list-style-type: none"> • Have you considered scheduling a meeting, site visits at your local hospital, educational lunch/dinners? • Who would you invite (locally) to such a meeting? • Name 3 organizations or people in your district that you would be interested in inviting to this meeting. 	
<p>What are the barriers to being able to host or schedule this meeting? How would you overcome these barriers?</p>	
<p>Do you have a peer, patient advocate in your area that has done something similar to this and can support you as you start your advocacy journey? (Who can you ask for help locally?)</p>	
<p>Is there a date/time of year to arrange something like this, keep in mind your health, election cycles in office, etc.</p>	

Empowering Patient Advocacy: Your Rights, Privacy Considerations

As you embark on your journey as a patient advocate, remember that you hold the power to effect change and improve healthcare policies. By understanding your rights to privacy and information, you can navigate this space with confidence, making a difference while safeguarding your personal health details.

In your advocacy efforts, you may be asked to share your medical experiences or participate in research or patient advisory boards. Ensure that you fully understand the purpose and potential impact of your involvement before giving **informed consent**.

Engaging with Congressional Offices

- When advocating with congressional offices, be mindful of sharing only the necessary medical information to support your cause.
- Respectfully request confidentiality of your personal health details during your advocacy discussions.

Participating in Patient Advisory Boards

- Patient advisory boards play a crucial role in shaping healthcare policies and pharmaceutical advancements.
- Before participating, understand the objectives, limitations, and any potential data sharing involved.

Balancing Privacy and Impactful Advocacy

1. PROTECTING YOUR EMOTIONAL WELL-BEING

- Advocacy can be emotionally taxing. Prioritize self-care and seek support from fellow advocates or mental health professionals.
- Share only what you are comfortable with, recognizing that you can advocate without divulging every personal detail.

2. FACT-CHECKING INFORMATION

- Verify medical information you come across during your advocacy journey, especially before sharing it with others.
- Trust reputable sources and consult healthcare professionals to ensure accuracy.

3. LEGAL AND ETHICAL CONSIDERATIONS:

- Understand the legal implications of sharing certain medical information and abide by ethical guidelines in your advocacy work.
- Seek legal advice or guidance from patient rights advocates if you encounter complex situations.





Interested in more?

Become a GLI Ambassador!

Upon graduating from GLI's Advanced Advocacy Academy, newly trained advocates have the opportunity to continue their journey as a GLI Ambassador. The GLI Ambassador program sharpens the skills of our advocates and then deploys them into the healthcare ecosystem to build relationships, expand patient knowledge, and increase involvement from other patients.

Clinical Trial & Research

GLI Ambassadors who are interested in the area of clinical trials and research design are trained to bridge communication gaps between research, clinical, and industry partners and the patient community to improve meaningful engagement in clinical trials. This ranges from advising researchers on clinical trial protocols to encouraging participation and educating patients on clinical trial opportunities.

Peer Support

GLI Ambassadors who are interested in peer to peer support will engage their newly learned skills and return to their communities to create a positive impact in myriad ways, such as learning how to become a peer mentor to creating local support groups.

Digital Health Navigation

GLI Ambassadors who are interested in the area of digital health navigation will work to improve digital health literacy in their communities, whether geographic or disease-specific; they will identify and be instrumental in eliminating some of the technological barriers patients face while navigating the healthcare system.

If you are interested in becoming a GLI Ambassador, please email us at Advocacy@globalliver.org

Peer to Peer Support

Social and emotional support are frequently identified among the top needs by patients and caregivers across the liver health landscape. Many factors contribute to stress and anxiety as patients encounter stigma often associated with liver disease, compounded by navigating complicated diagnostic journeys, disjointed care or health equity challenges, and financial and logistic barriers to accessing treatment. Support groups can help meet these needs. Patients, caregivers, and healthcare providers can start support groups. They can be led by trained peers and/or professionals.

What are types of support?

Type of Support	Definition	Benefits	Potential Sources
Emotional Support	offering empathy, concern, trust, acceptance, etc	<ul style="list-style-type: none"> • Connect with like-minded individuals • Decrease isolation • Increase knowledge about self, disease, choices, etc • Empowerment to manage disease • Encourage engagement and participation in personal care • Regain control lost from chronic/deadly disease diagnosis 	Individual counseling; support groups; discussion groups; conversations with friends and family
Tangible Support	provision of financial assistance, material goods or services	<ul style="list-style-type: none"> • Improve access to care to boost compliance • Practical needs met • Decrease stress • Relieve burden 	Co-pay assistance; grants; stipends; wigs; blankets; food; rides to appointments; etc
Informational Support	providing guidance, suggestions or useful information	<ul style="list-style-type: none"> • Increased knowledge about disease • Skills building to improve physician engagement • Decreased isolation • Empower engagement 	Patient education – brochures, programs; websites; decision support

Different styles of support groups

Social media groups (learn more about the different social media platforms in Appendix B)

Social media groups can quickly connect people/families who are affected by the same disease or share similar experiences.

- If there is already a social media group, reach out to the administrators and moderators (on Facebook these can usually be found on the About page for the group). If there is not a social media group, you may wish to start one. Using the disease name or associated gene in the title of the group can help others find it.
- These groups allow connections and conversations to exist without requiring a formal meeting time.

Online groups

These groups meet on Zoom, Google Meets, or another digital platform on a regular basis.



In-person groups

A traditional support group, these in-person, regularly scheduled meetings allow people in the same geographic community to meet at a central/community location and discuss topics related to their diagnosis or those of their loved ones.

Steps to create a support group:

1. Make a plan, including items such as target community, area of focus, and purpose.
2. Recruit members.
3. Establish guidelines.
 - Decide if the group will be facilitated or self-run.
 - Create a timeline (ongoing, quarterly, regularly refresh – make it straightforward to enter/exit).
 - Maintain confidentiality.
4. Provide resources for the recovery/healing process.

It is always good to remember that a support group is a safe place/environment for feelings and experiences to be shared. Members are advised to respect boundaries.

Navigating Digital Health

Navigating the many digital tools and sites that are necessary to manage and improve one's health can be challenging and requires staying up-to-date on many different skills.

Though it's no small task, staying eHealth-literate is important to advocate for your own care and empower other patients to be connected and informed. There are several pieces, including:

TRADITIONAL LITERACY

the ability to understand written language

TRADITIONAL NUMERACY

the ability to comprehend numbers, percentages, and calculations

HEALTH LITERACY

the ability to understand health information

COMPUTER LITERACY

familiarization and ability to navigate computer hardware and software

SCIENCE LITERACY

the ability to understand scientific concepts and publications

MEDIA LITERACY

the ability to process and evaluate the quality and content of media materials

INFORMATION LITERACY

the ability to process information, understand how it is organized, and know what to do with it

1. Privacy & Security in Patient-Generated Health Data

What's the difference between privacy and security?

Privacy

your own ability to control, identify, and regulate who has access to your personal information and health data

Security

the ability of the storage and access system that protects your data from being accessed by unauthorized people, whether through a breach, leak, or attack

U.S.: Health Insurance Portability and Accountability Act of 1996 (HIPAA)

This law regulates privacy and security for health data, but only for specific entities, mostly healthcare providers, such as doctors and hospitals.

E.U.: General Data Protection Regulation (GDPR)

This law regulates how personal data (including health data) are collected and processed by any organizations that target or collect data related to people in the EU (even if the company is

Where could your health data come from?

- Electronic health records (EHRs)
- Patient registries
- Mobile applications
- Wearable devices
- Online forums, social media posts



Whenever you are requested to share health information with an outside entity, you should consider asking the following questions:

- Do I have the ability to enable (or disable) my data from being used by a group/application?
- How and where will my data be used?
- How will my data be stored and protected?
- Will my data be de-identified before being stored, if participating in a registry or research program?

Why bother sharing your data?

1. Applications, wearables, and patient portals can provide extra information and context to help you manage your health.
2. Easy access to comprehensive data can allow you and your care team better track patterns in your health.
3. Participation in patient registries and research projects can help advance the field for better treatment and care for you and other patients.

2. Emails and Sign-Ons

Why are emails important?

- Appointment reminders or notifications of new test results may be delivered by email.
- Some treatment plans may involve information via email, whether prep instructions or educational materials on tips to improve your health or outcomes.
- News of breakthrough research, new clinical trials, or other topics related to your health may arrive via email.



3. Accessing & Sharing Your Health Data

PROXY ACCESS

Proxy access allows an authorized person who manages a patient's health care, whether a parent, child, sibling, or other caregiver, to view the patient portal to look at health data, schedule appointments, and sometimes even contact healthcare providers. This helps the person assisting manage the person's appointments and overall care while allowing the patient to maintain privacy for unrelated parts of their health data.

INTEROPERABILITY

Healthcare systems should be able to share and use data across platforms to allow your health data to move smoothly between systems or providers to allow for informed, continuous care no matter where you are.

4. Select & Connecting Health Apps

There are an overwhelming amount of health-related mobile apps that all have different features. First, ask yourself what you're looking for, both in terms of purpose and features. Being clear about what you're looking for will help narrow down which apps you might find helpful. There are three types of apps related to healthcare: healthcare insurance, healthcare provider/institution specific, as well as health, nutrition, and fitness apps.

1. Healthcare Insurance Apps (Aetna, Anthem, United Healthcare, etc.)

Most major healthcare insurance companies have their own app. Apps can provide access to your personal healthcare information, provide connection to care through appointment portals, help manage claims and more — so you can make the most of your benefits and take control of your health.

2. Healthcare Provider/Institution Apps (*hospital-specific patient portal access*)

Leading healthcare institutions around the world are using patient portal apps and websites as a platform to share information and stay connected to their patients. Apps can provide access to lab results, visit summaries, and general health data. Some patient portals provide a tool to message your doctors and nurses between visits, and some even allow you to integrate health data from wearables to give your healthcare providers extra context for your health.

3. Health, Fitness, and Nutrition Apps

Stay healthy and active with a wide range of apps that help you track fitness, manage nutrition, and achieve wellness goals. From workout routines to dietary suggestions, these apps offer personalized support for your health journey.

How Do I Find These Apps?

Your insurance providers and the hospital systems you use should have links to download their respective apps on their website.



5. Identifying and Understanding Credible Information

The Scientific Process

Research helps us explain and understand the world around us. Although there is plenty that we do know about the body (and the liver), there is much we don't know. To better understand and treat liver disease, for example, researchers might study the safety and usefulness of a new drug. This research, and any research, follows the scientific process:

- Step 1: Make an observation.
- Step 2: Form a hypothesis.
- Step 3: Make a prediction.
- Step 4: Conduct an experiment.
- Step 5: Analyze the results.



This means that the creation of new information – and, sometimes, information that changes the way we previously thought that something worked – is a valuable part of the process!

Qualities of credible sources

It's important to think about the type of information that you are searching for and who would have expertise about it. The sources that will have the best information about the patient experience, for instance, may be different from the sources that explain how liver cancer develops in the body.

PEER-REVIEWED (OR BASED UPON PEER REVIEWED SOURCES)

Other experts in the same field will read and evaluate the publication for accuracy and objectivity and recommend edits, approve, or deny it. Peer-review is a well-accepted indicator of reliable findings.

DEPTH OF INFORMATION

If a source is able to go into detail about a topic, it is likely founded on a strong basis of research.

AUTHORITY/EXPERTISE

Does the author have a degree or established expertise in the field? Are they affiliated with a reputable organization? It should make sense that the person who wrote the source is an expert on the topic and does not have conflicts of interest.

OBJECTIVITY

What is the purpose of the source? Is it to entertain, to change people's opinions, to present research, or to teach? A source that intends to teach or display information is likely to be more credible than one simply to entertain or persuade.

CURRENCY

Is a source up-to-date? If it was published a long time ago (5-10 years is a good rule of thumb), have subsequent studies by other researchers supported and expanded on the findings?



Examples of credible resources

- Journal of Hepatology
- JGH - Journal of Gastroenterology and Hepatology
- Healio Gastroenterology
- Centers for Disease Control website
- Mayo Clinic website
- Medline Plus
- Medscape

How to search a database

When you are planning to search for information, it is always a good idea to develop a search strategy to prepare.

- Select a database.
- Go to the search page.
- Enter your search terms into the search box.
- Use Boolean search techniques for best results.
 - Combine keywords using AND & OR rather than searching for a whole phrase.
 - Try combining synonyms with OR.
 - Use truncation (a shortened word) with an asterisk to search multiple similar words at once rather than typing them all out (ex. Using “hepat*” would include hepatology, hepatocellular, hepatologist, and more words)
- If you don’t have enough results, broaden your search using more keywords joined by OR. If you have too many results, narrow your search by combining more keywords with AND.
- You can filter your results by date of publication, source, or other category.
- After you have found several articles relevant to your interest, you can expand your search by looking at other articles by the same authors, articles that they have cited, or even “related articles” in the database.

Search



As you build your digital literacy, you can better navigate the health journey for yourself, your family members, and your community! As new technologies are released, it is extremely helpful to develop a baseline understanding of what they are, how they work, and how to use them. Still, the fundamentals of privacy & security, the scientific method, and trustworthiness remain the same.

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Appendix A: Liver Glossary

A

ABLATION

the complete or partial removal of a biological tissue or structure or destruction of its functionality; usually performed surgically but also accomplished via hormones, drugs, radiation, heat, or other methods

ABNORMALITY

condition or behavior that is considered unusual or different from normal physiology

ACETAMINOPHEN

a non-aspirin pain reliever and anti-inflammatory medication that can, if taken in excess, with alcohol, or by those with impaired liver function, may cause liver damage

ACUTE

a sudden and often severe onset of an illness

AFLATOXIN

toxins produced by *Aspergillus* fungi spores that grow on some crops (corn, peanuts, etc.); exposure to aflatoxins has been shown to correlate with an increased risk of developing liver cancer

AFP

alpha-fetoprotein; a protein found in the bloodstream that, in adults, is an indicator of possible liver cancer

ALAGILLE SYNDROME

genetic condition characterized by fewer than normal small bile ducts inside the liver that can cause bile buildup in the liver

ALBUMIN

a protein produced by the liver. Albumin blood tests help detect liver and kidney dysfunction.¹

Ranges: Normal ranges are between 3.5-5.5 g/dL

ALP

also ALK-PHOS; alkaline-phosphate; an enzyme mostly produced in the bile ducts and measured in liver function tests, but is not specific to the liver; high levels of ALP in the blood indicate liver injury

ALPHA-1 ANTITRYPSIN DEFICIENCY

an inherited disorder that can cause liver disease, jaundice, and cirrhosis

ALT

alanine aminotransferase; ALT is an enzyme that is mostly found in your liver, though it is in other parts of your body. A blood test for ALT can help doctors check the health of your liver. If your liver is damaged, ALT levels in the blood can increase.²

Ranges: Normal ranges are between 7 to 56 U/L (units per liter).

ALP

alkaline phosphatase; an enzyme found in the liver, but also in the kidneys, bones, and digestive system. Monitoring ALP levels in the bloodstream allows for early detection of a wide range of health conditions, including liver issues, bone disorders, and kidney disease.³

Ranges: Normal ranges are between 44-147 IU/L

ALTERNATIVE THERAPY

any type of healing that differentiates from mainstream medicine, including acupuncture, homeopathy, osteopathy

ANGIOGRAM

a medical imaging technique (x-ray, CT, or MRI) that helps visualize blood vessels and flow in the body; used to examine and identify tumor vascularity

APRI TEST

platelet ratio index; is a non-invasive way to determine the amount of fibrosis (scar tissue) present in the liver. The test measures AST and platelet levels which can indicate the overall health of the liver.⁴

Ranges: An APRI of less than 0.5 indicates a healthy liver with very minimal fibrosis. An APRI of greater than 1.5 suggests the presence of significant scarring of the liver tissue, or even cirrhosis.

ASCITES

abnormal collection of fluid in the abdomen oftentimes caused by liver failure

AST

aspartate aminotransferase; an enzyme found in the liver, heart, brain, pancreas, kidneys, muscles, and many other tissues in your body. High levels of AST in the blood can be a sign of an underlying medical condition such as liver disease.⁵

Ranges: Normal ranges are between 8-33 U/L.

ASYMPTOMATIC

having no signs or symptoms of disease

AUTOIMMUNE HEPATITIS

a disease that involves the body's immune system attacking its own liver cells, causing hepatic inflammation; untreated, autoimmune hepatitis can lead to cirrhosis and liver failure

AUTOIMMUNE

a condition in which the body's immune system

B

BENIGN

not malignant or cancerous; benign tumors do not invade surrounding tissue or metastasize to other parts of the body
Bile duct cancer: or cholangiocarcinoma; a rare cancer that forms in the bile ducts; extrahepatic bile duct cancer is found outside the liver

BILE DUCT CANCER

or cholangiocarcinoma; a rare cancer that forms in the bile ducts; extrahepatic bile duct cancer is found outside the liver

BILE DUCT

a tube that carries bile from the liver to the gallbladder for storage and then to the intestines for use in digestion

BILE

yellow-green liquid that is excreted from the liver, stored in the gallbladder and passes into the small intestine to aid in the digestion of food by breaking down fat

BILIARY ATRESIA

a congenital disorder characterized by malformation of the biliary tract in which biliary ductules fail to adequately form and cannot collect bile from the liver

BILIRUBIN

the yellow pigment that results from the breakdown of hemoglobin (the pigment in red blood cells). Lower than normal bilirubin levels are usually not concerning but high levels of bilirubin in the bloodstream can indicate issues with the liver or bile ducts.⁶

Ranges: Normal ranges are between 0.3 - 1.2 mg/dL

BIOLOGIC RESPONSE MODIFIERS

naturally occurring or manufactured substances that can suppress or stimulate the immune system to help fight cancer, lessen treatment side effects, or target and destroy cancer cells

BIOLOGIC THERAPY

a treatment that stimulates or suppresses the body's own immune system to help the body to fight cancer cells; also *immunotherapy*

BIOMARKER

measurable substance or physiological activity in the body that can be used as a sign of stable condition, an abnormal state, or disease; can be used to determine how well the body responds to new treatments

BIOPSY

removal and examination of a small piece of body tissue

BUDD-CHIARI SYNDROME

a rare liver disease that occurs as the veins that drain blood from the liver are narrowed or blocked

BUN

blood urea nitrogen; A BUN test measures how much urea nitrogen is in your blood, which indicates how well your kidneys are working.⁷

Ranges: Normal ranges are between 6 to 24 mg/dL (2.1 to 8.5 mmol/L)



CANCER

a disease in which abnormal cells divide rapidly and uncontrollably and can invade nearby tissues and sometimes spread to other parts of the body

CARCINOGEN

substance that can cause cancer, such as tobacco smoke

CARCINOMA

cancers that originate in the skin or in tissues covering internal organs

CEA

carcinoembryonic antigen; a substance present in the blood of people who have certain cancers or who smoke tobacco; CEA levels can be used to help track treatment efficacy and cancer recurrence

CHEMOEMBOLIZATION

a procedure that prevents blood flow to tumors after anticancer drugs are administered to the area; a common treatment method for liver cancer

CHEMOTHERAPY

a cancer treatment that uses drugs to stop the growth of cancer cells by killing cancer cells or preventing them from dividing; can be given via mouth, injection, infusion, skin

CHILD-PUGH SCORE

a score based on five clinical features that can be used to determine prognosis of chronic liver disease and cirrhosis or with the MELD score to determine liver transplantation priority; the five clinical features are: total bilirubin level, serum albumin, international normalized ratio, degree of ascites, and degree of hepatic encephalopathy

CHOLANGIOCARCINOMA

a rare cancer that forms in the bile ducts

CHOLANGITIS

irritated or inflamed bile ducts causing poor bile flow from the liver and potentially causing damage to hepatocytes

CHOLECYSTECTOMY

surgical procedure done to excise (remove) the gallbladder

CHOLESTASIS

interrupted bile flow through the biliary system resulting in reduced bile reaching the intestine

CHRONIC

disease or condition which persists over a period of time, usually with a gradual onset

CIRRHOSIS

a condition characterized by scarring of and damage to the liver; cirrhosis inhibits normal liver function and can be caused by viral, genetic, autoimmune, bacterial, and lifestyle diseases

CLINICAL STAGE

the phase of progression of cancer in the body, based on physical examination, imaging tests, and biopsies of cancerous areas

CLINICAL TRIAL

research study that aims to answer medical questions and solve health problems; a study that evaluates new drugs, procedures, or devices

COMBINATION THERAPY

therapy that integrates more than one method of treatment

COMORBIDITY

a condition that is present with another simultaneous disease

COMPLEMENTARY THERAPY

the use of alternative treatments together with conventional therapies

CONGENITAL

a condition or disease present at or before birth

CONTRAST

a dye or other substance used during x-rays, CT scans, MRI, or other imaging tests that can highlight abnormal areas inside the body

CREATININE

a substance that made by the body and used to store energy that may have potential as a treatment for weight loss related to cancer

CRYOABLATION

procedure in which cold liquid or a cryoprobe is used to freeze and destroy abnormal tissue; can be used to treat certain types of cancer; also cryosurgery or cryotherapy

CT SCAN

computerized tomography; diagnostic imaging tool that uses x-rays to create detailed pictures of the body

CURATIVE THERAPY

treatment performed to cure a condition (as opposed to treating symptoms); in localized cancer can be the removal of all cancerous tissue

D

DEFERRED THERAPY

withholding therapy or treatment and tracking a patient's condition over time with tests and exams to detect early signs of disease appearance or progression

DIAGNOSIS

identification of a disease, condition, or injury from a patient's signs and symptoms

DISTANT METASTASIS

cancer that has spread from the original tumor to different organs or other lymph nodes

DNA

deoxyribonucleic acid; hereditary material present in all cells that carries genetic information and passes it from one generation to the next

DONOR

a person who donates an organ, tissue, or blood to another person

DRUG RESISTANCE

the failure of cancer cells to respond to medicine or treatment

DYSPLASIA

abnormal changes in the structure or organization of a group of cells which can be an indicator of cancer

E

EBRT

external beam radiation therapy; a type of radiation therapy that uses a machine to aim high energy rays at cancer from outside of the body

EGF

epidermal growth factor; a protein produced by cells and some tumors that signals cell growth and differentiation

EGFR

epidermal growth factor receptor; a protein found on the surface of cells that binds to EGF and causes cells to divide; EGFR is found at high levels on many cancer cells

ENCEPHALOPATHY

a disorder of the brain that can result from disease, injury, drugs, or chemicals; can often be caused by advanced liver disease

EPIDEMIOLOGY

the study of the patterns, causes, and control of disease in groups of people

ERCP

endoscopic retrograde cholangiopancreatography; an endoscopic x-ray of the pancreatic duct, hepatic duct, common bile duct, duodenal papilla, and gallbladder

ESLD

end-stage liver disease

EUS

endoscopic ultrasound; a procedure in which an endoscope containing an ultrasound device is inserted into the body to create an image of internal organs removal by surgery

EXTERNAL RADIATION THERAPY

a form of radiation therapy where high energy rays are projected at the body from a machine; usually requires outpatient care at a treatment facility for 4-5 days a week for several weeks

EXTRAHEPATIC

located or occurring outside the liver

F

FATTY LIVER DISEASE

accumulation of fat in the liver that causes abnormal liver function

FIBROLAMELLAR HEPATOCELLULAR CARCINOMA

a rare liver cancer usually diagnosed in adolescents and young adults who have no history or early symptoms of liver disease

FIBROSCAN®

a non-invasive technology used to quantify fibrosis and steatosis

FIBROSIS SCORE

estimates the amount of scarring in the liver

FIBROSIS

formation of scar tissue in place of normal tissue

FIRST LINE TREATMENT

the first treatment given for a disease; often a group of treatments, such as surgery followed by chemotherapy and radiation also primary treatment

FNAB

fine needle aspiration biopsy; the removal of tissue or fluid with a thin needle for examination under a microscope; *also FNA biopsy*

G

GALLIUM SCAN

a diagnostic test that involves injecting the chemical gallium into the veins to detect cancer cells and inflammation

GASTROENTEROLOGIST

doctor who specializes in digestive diseases

GENE

the functional and physical unit of heredity passed from generation to generation; a segment of DNA that codes information for making specific proteins which can form physical characteristics, such as height or eye color

GENE THERAPY

a new and rapidly growing field of medicine that inserts foreign or altered genetic material (DNA or RNA) into the body to correct specific disorders or to help fight disease

GFR

glomerular filtration rate; the estimated rate at which the kidneys filter blood to remove any toxins or waste. Being aware of your GFR can help with early detection of kidney disease, diabetes, and other health conditions. A higher GFR indicates better kidney function.⁸

Ranges: Average is about 116 mL/min/1.7m²

GGT

gamma glutamyl transpeptidase; an enzyme produced by the liver and found in the liver, kidneys, heart, brain, and pancreas. Blood GGT levels can indicate liver or bile duct issues at a very early stage.⁹

Ranges: 5-40 U/L (units per liter)

GLOBULINS

this test measures your blood levels of a protein called globulin, which is used to determine the health of your immune system.¹⁰

Ranges: Normal ranges are between 2.0 to 3.5 g/DL (grams per deciliter) or 20 to 35 g/L (grams per liter).

GRADE

in cancer, indicates how aggressive a cancerous tumor is; lower grade can indicate a slower form of cancer growth and spread; higher grade can indicate more aggressive cancer; also histologic grade

H

HbA1c

hemoglobin A1c; is a blood test that shows what your average blood sugar level was over the last 2-3 months. Monitoring blood sugar levels are important as they can help prevent or delay long-term health complications such as diabetes.¹¹

Range: Normal: Normal ranges are between 5.7% - 6.4%

HEMATOLOGIST

a doctor who specializes in treating blood disorders

HEMOCHROMATOSIS

an inherited genetic disorder characterized by abnormally high iron absorption in the intestines causing high levels of iron storage in the liver and several other organs. Hemochromatosis can cause cirrhosis and liver failure

HEPATECTOMY

surgery to remove all or part of the liver

HEPATIC ARTERY

the major blood vessel that delivers blood, oxygen, and nutrients to the liver

HEPATIC DYSFUNCTION

loss of proper liver function

HEPATIC ENCEPHALOPATHY

neuropsychological abnormalities due to liver dysfunction

HEPATIC

relating to the liver

HEPATITIS A

caused by the hepatitis A virus; spread by contact with food, water, or other materials that have been contaminated with the blood or stool of an individual infected with hepatitis A

HEPATITIS B

caused by the hepatitis B virus; transmitted through the bodily fluids of an individual infected with hepatitis B; there is a vaccine for hepatitis B that has had a notable decrease on incidence of hepatitis B since its discovery

HEPATITIS C

caused by the hepatitis C virus; transmitted through contact with the blood of an individual infected with the hepatitis C virus; there is a cure for hepatitis C, but it is costly and not always covered by insurance

HEPATITIS D

caused by the hepatitis D virus; hepatitis D can only occur in individuals who are also infected with the hepatitis B virus; transmission of hepatitis D occurs in the same ways as hepatitis B, so the hepatitis B vaccine is effective in also preventing hepatitis D

HEPATITIS E

caused by the hepatitis E virus; spread by contact with food, water, or other materials that have been contaminated with the feces of an individual infected with hepatitis E; Hepatitis E is very rare in the United States and is more common in underdeveloped regions of the world; may also be transmitted through contact with wild boar and pigs

HEPATITIS G

a newly discovered form of hepatitis, hepatitis G is believed to be spread through contact with the blood of those infected with the hepatitis G virus, most commonly through intravenous drug use; also infects individuals with clotting disorders such as hemophilia and individuals who rely on hemodialysis for kidney failure

HEPATITIS

swelling and inflammation of the liver

HEPATOBIILIARY

having to do with the liver, bile ducts, and/or gallbladder

HEPATOCELLULAR CARCINOMA

most common form of primary liver cancer

HEPATOLOGIST

a doctor who specializes in liver health and disease

HEPATOLOGY

the study of the liver

HEPATOMEGALY

enlargement of the liver causing it to be felt below the ribs

HIGH-RISK CANCER

cancer that is likely to recur or spread

HILAR CHOLANGIOCARCINOMA

a carcinoma that develops at the junction of the right and left hepatic bile ducts

HISTOLOGIC GRADE

in cancer, indicates how aggressive a cancerous tumor is; lower grade can indicate a slower form of cancer growth and spread; higher grade can indicate more aggressive cancer; also *grade*

HOSPICE

a special type of care for people who are in the end stages of their disease and have stopped treatment; care, either outpatient or inpatient, is focused on alleviating pain and managing symptoms

HYPOFRACTIONATION

a treatment schedule in which the total dose of radiation is divided into smaller doses, which are given daily



ICTERIC

technical term for jaundice

IDIOPATHIC

condition or disease of unknown cause

IGRT

image-guided radiation therapy; a procedure that uses a CT, X-ray, or other imaging techniques to create a picture of a tumor to help guide the radiation beam during radiation therapy

IMAGING STUDIES

non-invasive tests that can produce detailed pictures of the body's organs and structures; include x-rays, CT scans, MRI, and ultrasound

IMMUNE SYSTEM

network of cells, tissues and organs, which includes white blood cells and lymph nodes, that helps protect the body from disease and prevent infection

IMMUNO-ONCOLOGY

the study and development of treatments that take advantage of the body's immune system to fight cancer

IMMUNOSUPPRESSANT

any medication that causes the body's immune system to weaken or stop working

IMMUNOSUPPRESSION

a condition that causes the body's immune system to decrease in effectiveness; can be caused by disease or certain drugs such as chemotherapy

IMMUNOTHERAPY

a treatment that stimulates or suppresses the body's own immune system to help the body to fight cancer cells; also *biologic therapy*

IMRT

intensity-modulated radiation therapy; type of 3D radiation therapy that uses computer-generated images to show the size and shape of the tumor without damaging nearby healthy tissue

IN SITU

“in its original place”; cancer in which abnormal cells are found only in the original site of formation

INFUSION

injection of fluids, including medication, into the bloodstream

INTERNAL RADIATION

radiation therapy in which radioactive material is introduced surgically into a tumor, swallowed, or injected into the bloodstream

INTERVENTIONAL RADIOLOGY

minimally invasive, image-guided treatment of medical conditions that once required open surgery that instead use ultrasound, X-rays, CAT scans, MRI scans or other innovative methods

INTRA-ARTERIAL

within an artery

INTRAHEPATIC

within the liver

INVASIVE CANCER

cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues

J

JAUNDICE

a yellow appearance to the skin and sclerae (whites of the eyes) and darkening of urine caused by an excess buildup of bilirubin in the blood due to liver failure or blockage of bile ducts

K

KASAI PROCEDURE

treatment method for biliary atresia that restores bile flow

L

LAPAROSCOPIC SURGERY

surgery done with a laparoscope, a small, thin, tube-like instrument with a light and lens

LESION

area of abnormal tissue; could be cancerous

LIQUID BIOPSY

test done on a blood sample to look for cancer or DNA fragments of tumor cells

LIVER ENZYME TEST

also liver function test; range of blood tests that examine how well the liver and biliary system function

LDH

lactate dehydrogenase; an important enzyme found in the muscles, kidneys, liver, and red blood cells. LDH tests help detect any widespread tissue damage within the body.¹²

Ranges: for people assigned male at birth: 135-225 U/L (units per liter); for people assigned female at birth: 135-214 U/L.

LOCAL CANCER

malignant cancer with margins entirely inside the organ where the cancer began

LYMPH NODES

small structures that are part of the body's immune system that filter lymphatic fluid and help fight disease and infection

LYMPHADENECTOMY

procedure in which lymph nodes are removed from the body and a lymph node sample is examined for signs of cancer

M

MALIGNANT

tumor that has the potential to spread to other parts of the body; also *cancerous*

MARGIN

the edge or border of tissue removed in cancer surgery; can be negative (no cancer found at the margin and all cancer has been removed) or positive (cancer found at the margin and not all cancer has been removed)

MELD SCORE

Model for End-Stage Liver Disease; measure of mortality risk in patients with end-stage liver disease used as a disease severity index to help prioritize allocation of organs for transplant

METABOLIC SYNDROME

condition marked by extra fat around the abdomen, high levels of blood glucose, high levels of triglycerides in the blood, low levels of high-density lipoproteins in the blood, and high blood pressure; also *metabolic syndrome X*

METASTASIS

spread of cancer cells to different parts of the body

MICROWAVE THERAPY

treatment in which body tissue is exposed to high temperatures to damage and kill cancer cells or to make them more sensitive to radiation and anticancer drugs

MRE

magnetic resonance enterography; diagnostic imaging tool used to assess certain gastrointestinal disorders

MRI

magnetic resonance imaging; diagnostic imaging tool that uses magnets, radio frequencies, and computers to images of structures inside the body; a safe and painless test that uses a magnetic field and radio waves to produce detailed pictures of the body's organs and structures

MULTIDISCIPLINARY

treatment planning approach or team including a number of doctors and other experts in different specialties

MUTATION

any change in a gene

N

NAFLD

nonalcoholic fatty liver disease

NASH

nonalcoholic steatohepatitis; the severe form of NAFLD

NEOADJUVANT THERAPY

first step treatment used to shrink a tumor before secondary treatment, usually surgery; can include chemotherapy, radiation therapy, and hormone therapy

NIDDK

National Institute of Diabetes and Digestive and Kidney Diseases

NODULE

growth or lump that could be cancerous

NONINVASIVE

in medicine, procedure that doesn't require inserting any tool through the skin or into a body opening; in cancer, disease that has not spread outside its primary location

**OBSTRUCTION**

the blockage of a blood vessel, bile duct, or other body passageway

ONCOGENES

genes that cause cells to grow and duplicate, that under certain circumstances can mutate and cause abnormal cell growth and cancer

ONCOLOGIST

doctor who treats patients with cancer

ONCOLOGY

the medical field that involves the diagnosis and treatment of cancer

OPERABLE

a condition that can be treated with surgery

P

PALLIATIVE CARE

treatment given to relieve the symptoms and reduce the suffering caused by cancer; usually given together with other cancer treatments, from diagnosis, through treatment, survivorship, remission, and end of life

PATHOLOGIC STAGE

cancer stage determined after surgery to remove and examine a tumor or to explore the extent of cancer; usually combines the results of both the clinical staging (physical exam, imaging test) with surgical results

PATHOLOGIST

a physician who specializes in diagnosing and classifying diseases by studying cell and tissue samples

PBC

primary biliary cholangitis; a chronic liver disease in which bile ducts become inflamed and destroyed causing bile and toxic substances to build up in the liver; can lead to scarring, cirrhosis, liver failure, and liver cancer

PBRT

proton beam radiation therapy; type of radiation therapy that uses streams of protons to kill tumor cells; can reduce the amount of radiation damage to healthy tissue near a tumor

PERCUTANEOUS ALCOHOL INJECTION

injection of ethanol through the skin directly into a tumor to kill cancer cells; usually guided by ultrasound or CT scan; also *alcohol ablation*, *ethanol ablation*, *PEI*

PERCUTANEOUS

passing through the skin; injection or a topical medicine

PERFORMANCE STATUS

a measure of how well a patient is able to perform ordinary tasks and carry out daily activities

PERITONEUM

the tissue that lines the abdominal wall and covers most of the organs in the abdomen

PET SCAN

positron emission tomography scan; imaging test that involves intravenous injection of radioactive glucose and following scan identify and locate cancerous cells in the body

PORTAL HYPERTENSION

high blood pressure in the vein that carries blood to the liver from the stomach, small and large intestines, spleen, pancreas, and gallbladder

PORTAL VEIN

blood vessel that carries blood to the liver from the intestines, spleen, pancreas, and gallbladder; also *hepatic portal vein*

PRIMARY TREATMENT

the first treatment given for a disease; often a group of treatments, such as surgery followed by chemotherapy and radiation; also first line treatment

PRIMARY TUMOR

the original, first tumor occurring in the body; cancer cells from a primary tumor may spread to other parts of the body and form new, or secondary, tumors

PROGNOSIS

the likely outcome or course of a disease; the chance of recovery or recurrence; an estimate of how well a person's treatment is working and how likely or unlikely it is that cancer will recur

PRURITUS

severe itching

PSC

primary sclerosing cholangitis; autoimmune disease causing scarring, irritation, and narrowing of bile ducts both inside and outside of the liver

PT

prothrombin time; Prothrombin is a protein produced by the liver to help with blood clotting. Determining your PT allows your doctor to evaluate how your blood is clotting and check for liver issues.¹³

Ranges: If your PT results are presented in seconds, the normal range is 10-13 seconds. If your PR results are presented in international normalized ratio (INR), values of 1.1 or below are considered normal.

PTC

percutaneous transhepatic cholangiography; a procedure that uses x-ray to examine the hepatic and common bile ducts after a contrasting agent is injected into the liver or bile duct

PTCD

percutaneous transhepatic cholangio drainage; a procedure used to drain bile and relieve pressure in the bile ducts caused by a blockage

PTLD

post transplant lymphoproliferative diseases; a condition occurring in transplant patients that is likely caused by an interaction between the Epstein-Barr virus and immunosuppressant drugs; PTLD can progress until it becomes lymphoma, a cancer of the blood

R

RADIATION THERAPY

the use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors

RADIOFREQUENCY ABLATION

procedure that uses radio waves to heat and destroy abnormal cells

REGIONAL LYMPH NODES

in oncology, a lymph node that drains lymph from the region around a tumor

REJECTION

attack of the body's immune system on a transplanted organ as though it were diseased or injured; can be acute, with sudden onset, or chronic, which happens over a long period of time and is less likely to respond to treatment

RELAPSE

return of a disease or the signs and symptoms of a disease after a period of improvement

REMISSION

decrease in or disappearance of signs and symptoms of cancer

RESECTABLE

able to be removed by surgery

RESIDUAL DISEASE

cancer cells that remain after attempts to remove the cancer have been made

RESTAGING

used to determine the extent of the disease if a cancer comes back after treatment

REYE'S SYNDROME

acute and severe childhood liver disease that occurs after acute viral illness and acetaminophen use

RISK FACTOR

something that increases the chance of developing a disease; cancer risk factors include age, family history, tobacco use, exposure to radiation or other chemicals, infection with certain viruses or bacteria, and certain genetic mutations

S

SBRT

stereotactic body radiation therapy; a type of external radiation therapy that uses special equipment to position a patient and precisely deliver radiation to tumors in the body, sparing healthy tissue

SCLERAE

whites of the eyes

SCREENING

checking for disease when there are no symptoms with the hope of finding disease at early stages

SECOND OPINION

seeking a diagnosis and/or treatment plan from another doctor after initial diagnosis and treatment planning

SECONDARY CANCER

cancer that has spread from the place where it originated to another part of the body; secondary cancers are the same type of cancer as the original cancer

SIDE EFFECTS

a problem that occurs when treatment affects healthy tissues or organs; can include nausea, vomiting, fatigue, pain, decreased blood cell counts, hair loss, and mouth sores

SONOGRAPHY

diagnostic imaging tool that uses high-frequency sound waves and computers to create images of tissue, organs, and vessels; also ultrasound

STAGING

performing exams and tests to determine the extent of the cancer within the body, especially to determine whether the disease has spread from where it first formed to other parts of the body

STENOSIS

abnormal narrowing of a body opening; also *stricture*

STEROID

medication meant to reduce the activity of the body's immune system

STRICTURE

abnormal narrowing of a body opening; also *stenosis*

SUPPORTIVE CARE

care given to improve the quality of life of patients who have a serious or life-threatening disease

SURGERY

a procedure used to remove or repair a part of the body or to find out whether disease is present

SURVEILLANCE

closely watching a patient's condition but not treating it unless there are changes in test results

SURVIVAL RATE

the percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease

SURVIVORSHIP

the health and life of a person with cancer post treatment until the end of life; covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases

SYMPTOM

a physical or mental problem that a person experiences that may indicate a disease or condition; cannot be seen and do not show up on medical tests; include headache, fatigue, nausea, and pain

SYSTEMIC CHEMOTHERAPY

treatment with anticancer drugs that travel through the blood to cells throughout the body

SYSTEMIC DISEASE

disease that affects the whole body

T

TACE

transarterial chemoembolization; procedure in which anticancer drugs are placed near a tumor's vessels to block its blood supply in the hopes of slowing tumor growth or killing the tumor

TAE

transarterial embolization; procedure in which small gelatin sponges or beads are placed in a tumor's vessels to block its blood supply in the hopes of slowing tumor growth or killing the tumor

TARGETED THERAPY

drugs or other substances that block the growth and spread of cancer by interfering with specific molecules involved in the growth, progression, or spread of cancer

TERMINAL CANCER

cancer that cannot be cured will lead to death; also end-stage cancer

THERMAL ABLATION

procedure that uses heat to remove a tissue or destroy its function

TRANSFUSION

procedure in which blood or parts of blood are injected into a patient's bloodstream through a vein; also blood *transfusion*

TRANSPLANT

surgical procedure that involves removing a diseased liver and replacing it with a liver or part of a liver that functions adequately

TUMOR BURDEN

number of cancer cells, the size of a tumor, or the amount of cancer in the body; also *tumor load*

TUMOR

mass of abnormal cells

U

ULTRASOUND

diagnostic imaging tool that uses high-frequency sound waves and computers to create images of tissue, organs, and vessels; also *sonography*

V

VACCINE THERAPY

a treatment that uses a substance or group of substances to stimulate the immune system to destroy a tumor

Appendix B:

Social Media

Glossary

ALGORITHM

On social media, the “algorithm” determines what content shows up on a feed in a particular order. Algorithms are typically kept secret and continuously updated by each platform.

ANALYTICS

Analytics is the general term for both the tools used to analyze social media and the results of those tools.

APPLICATION

Application, or app, is the best way to access social media platforms from a mobile device.

BIO

A bio, short for biography, is a quick introduction to you and your profile.

BLOCK

To stop a user from seeing your content (and to also permanently stop seeing their content), you can use the block feature. Once a user is blocked, they will not be able to engage with your profile at all.

BLOG

A blog is a place online to publish content that usually focuses on a central topic. Blogging is a great way to share longform content on a subject you care about.

CAMPAIGN

A social media campaign is a scheduled and organized effort to spread information about your platform and reach out to your target audience.

CAPTION

A caption is a place to describe your content further. For example, an Instagram caption is a great opportunity to expand on your personal story. Captions can also include tags and mentions, which can help with post engagement.

CROSS-CHANNEL

Cross-channel marketing describes marketing efforts that stretch across social media platforms.

ENGAGEMENT

Engagement is indicated by several social media metrics including likes, shares and mentions. High engagement and social media interaction is desired.

GEOTAG

A geotag adds a location to your posts. Geotags are useful because social media users can search content by location.

HYPERLINK

A hyperlink is a link embedded in content that can be followed by clicking through to another piece of content.

IMPRESSIONS

Impressions are a metric that shows how often your post is seen on a social media platform. Impressions are a good indicator of the reach of your content.

LIVE STREAM

Live streaming is a video shared in real time on social media. Several social media platforms have this capability including Facebook, LinkedIn, Instagram, TikTok, and YouTube.

LOCATION SETTINGS

Location settings allow you to link your specific location to a post. Location settings are also used to show you relevant content to your area.

METRICS

Metrics is how one can quantitatively measure social media success. Metrics takes into account the number of likes, shares, and comments.

MUTE

An alternative to the unfollow. To mute a user is to stop seeing a user's content on your feed without unfollowing them.

NOTIFICATION

A notification is an alert of new social media activity. You will receive a notification when someone has engaged with your content.

PLATFORM

A platform is another way to refer to a specific social media site. LinkedIn, Twitter, and Instagram are all examples of platforms.

PODCAST

A podcast is an audio file uploaded to the internet or social media. A podcast usually focuses on a central topic.

POLLS

Several social media platforms have the capability to run polls. Polls are a great, interactive way to engage with a social media audience and survey public opinion.

PRIVACY SETTINGS

Privacy settings ensure only those who you want to be able to view your profile can view it. It is important to update your privacy settings often.

PRIVATE MESSAGE

A private message is a message thread that can not be seen by the public. On some social media platforms, private messages are called Direct Messages, or DMs.

REACH

Reach is a social media analytic tool that tells you how many people your social media content has been exposed to.

SEARCH

The search function on social media platforms is used to find specific content you are looking for. For example, you can search for a hashtag or a social cause.

SOCIAL MEDIA

The catch-all term for platforms that are used for social networking.

TAG

A tag links to a profile, page, group, or hashtag and can be used in a post or in

TARGET AUDIENCE

Target audience is the group of people you want to reach with your social media content. You can target a specific audience by tailoring content to their interests.

THREAD

A thread is a string of posts, comments, and replies that are all part of a single conversation.

UNFOLLOW

To stop seeing a user's content, you can unfollow. Unfollowing someone on social media takes them off the list of users you see posts from in your feed.

Platform-Specific Social Media Glossary

Facebook

COMMENT

A comment is one way to engage with a post. A comment is a good way to ask a question or express praise or concern.

FRAME

A Facebook Frame allows you to add a graphic or visual message to your profile picture. Frames can be used to promote a social cause or message you care about.

FRIEND

A friend is a connection on Facebook. When you accept a friend request or your friend request is accepted, you will see their content and vice versa.

GROUP

A group is a collection of like minded individuals within a social media network. A Facebook group is a great way to discuss liver issues and share relevant information.

MESSENGER

Messenger is Facebook's direct messaging platform. Using Messenger, you can send and receive direct messages. You can also video call on Messenger. The circle represents the instant video call feature, which appears when viewing the same conversation with your Facebook friend. When it appears, you can tap on it to start a video call with your friend, as they are available to accept the video call or reject it.

NEWS FEED

Your news feed is populated by all the new content and updates from the users you follow.

PROFILE

An individual's personal account, where they can post updates, upload photos, share videos, maintain a friends list and provide personal information.

PAGE

The account for a business, organization, or institution. Pages have the basic same functions as Facebook profiles with the added ability to advertise and track performance.

POST

A post is any update or content shared on social media.

PROFILE PICTURE

A profile picture is an image that, combined with your name, helps others identify you on social media.

REACTIONS

Reactions are a way to engage with a Facebook post. The main reaction is a "like" but you can also use "love", "laugh", "wow", "sad" and "angry" reactions on Facebook.

SHARE/REPOST

A repost is one way to share content that another user posted. On Facebook, a repost is known as a share.

WATCH PARTY

A Watch Party allows for all participants to watch a video at the same time. During a Watch Party, participants can watch and react to a video in real-time.

Instagram

ARCHIVE

Hiding old posts without deleting them. You'll be able to see archived posts by tapping "Archive" (3 dots, top right hand corner of your profile).

CAPTIONS

A brief description that appears underneath a photo. Captions might include a call to action, a funny quote, or explain the story behind a picture. Captions are the place for hashtags too.

DIRECT MESSAGE

An in-app messaging tool that allows users to privately exchange text, photos, posts and stories with one or more people. You can also call and video call anyone you have an active direct thread with. In groups you can video chat to up to four people at a time, and the video will expand as more friends join.

GUIDE

Instagram Guides are like a miniature blog right on Instagram. They let users scroll through a curated flow of content (or album of aggregated posts that are of the same category) with added commentary — similar to a blog post.

HANDLE

Your unique, identifying name on social media

HASHTAG

A hashtag, denoted by the “#” symbol, is usually a keyword or phrase that indicates what your content is about. Hashtags are searchable and are used across social media platforms.

REPOST

A repost is one way to share content that another user posted.

STORIES

Instagram Stories are another way to share content on Instagram, other than a post. Instagram stories expire after 24 hours.

STORIES HIGHLIGHTS

appear on your profile, below your bio

REELS

Full screen vertical 15-90 second videos user can create, edit, and post to their profiles within the app. Unlike Instagram Stories, Reels won't disappear after 24 hours, and they're easy to save or share.

THREADS

An app created by Instagram where you can post threads (similar to Twitter), reply to others and follow profiles you're interested in. Threads and replies can include short pieces of text, links, photos, videos or any combination of them. People can also follow you to see your threads and replies in their feeds and from your profile.

LinkedIn

ARTICLE

Like a blog post or news article that is posted by a LinkedIn user, hosted on the LinkedIn website, and connected to their account

COMPANY PAGE

The official page for a company or agency, which can be followed, post or share content, be linked to by employees, and can even post available job openings

CONNECTION

LinkedIn's version of a Facebook “friend.” Once you connect with someone, they are in your LinkedIn network and you can each see each other's content.

ENDORSEMENTS

An endorsement occurs when someone vouches for a specific skill of yours on LinkedIn. An endorsement highlights your credibility as a professional.

GROUP

Like a Facebook group, groups exist to bring together posts and conversations around common interests, schools, geographic regions, or something else

LIVESTREAM

LinkedIn allows company pages and certain users to broadcast a live video feed and even promote it as an event in advance of the livestream.

SKILLS

You can add your unique skills to your LinkedIn profile. Skills highlight your professional strengths.

TikTok

DISCOVER PAGE

The Discover page is TikTok's home-base for all things trending. Click the magnifying glass labeled "Discover" at the bottom of the TikTok app to get to the Discover page. Here you'll find the trending hashtags of the day, popular sounds, and branded hashtag challenges.

DUETS

A feature that allows a creator to collaborate with another user's video. You can only Duet with someone with the permission of the respective creator.

FOR YOU PAGE

TikTok's main landing page and the first thing you see when you open the app. The For You Page is full of recommended videos that are tailored to each user

HEARTS

You can show your admiration for a video by clicking the heart on the right-hand side of the screen. Clicking the heart will auto-generate a collection within your own profile, collecting all of your favorite videos so you can view them later.

INBOX

where you can check all your recent activities. There is an Activities section that offers info on such things as how many people viewed your profile and available videos on how to use TikTok. A Messages section lets you know if you have new followers and if you've shared any videos. You can also pick out people from your contacts list or from a list of "people you may know" to follow.

PROFILE

This is what you create about yourself that's unique to you. People will see your username, a short bio, a count of how many people are following you and who are following, and all the public videos you've created.

YouTube

AVERAGE PERCENTAGE VIEWED (APV)

Percentage of your video a viewer watched before clicking off.

AVERAGE VIEW DURATION (AVD)

How much of your video a viewer watched.

CARDS

Popups that display on the right-hand side of the screen while a video is playing. Creators can set the cards to be a video, playlist, website or channel.

CHANNEL

A YouTube page is commonly referred to as a "channel".

CHANNEL KEYWORDS

Terms that give YouTube information and context about your channel. Specifically, they help YouTube understand the type of content you produce and who your target audience is.

SHORTS

YouTube Shorts are short-form, vertical 15-60 second videos created using a smartphone and uploaded directly to YouTube from the YouTube app.

SUBSCRIBER

A follower on Youtube

TAG

On YouTube, tags are keywords added to content so it is searchable. When uploading a YouTube video, make sure to tag your video with relevant and descriptive keywords. Properly tagged YouTube videos are more likely to be found.

THUMBNAIL

Cover image for a video that has a resolution of 1280×720 (with a minimum width of 640 pixels). Thumbnails are uploaded in image formats such as JPG, GIF, or PNG, and must be under the 2MB limit. Try to use a 16:9 aspect ratio, as it's the most used in YouTube players and previews.

VIEWS

Indicate how many times your video has been watched

VLOG

A video blog. A vlog is a great way to share your personal story.

X, Formerly Known as Twitter

CHAT

A Twitter chat is a live tweet-based discussion that occurs at a specified date and time about a topic of interest. Users can participate in Twitter chats by using the designated hashtag, retweeting chat tweets, and engaging with the chat's featured users.

FAVORITE/LIKE

A favorite or a like indicates that someone "likes" or enjoys your content; indicated by a red heart icon

FOLLOWER

A follower is someone who subscribes to see your posts in their feed

QUOTE REPOST

Formerly quote retweet; Like a repost, but you can add your own content to the original tweet

REPOST


Formerly retweet; another account's post that is added to your profile like other posts and is viewable to your followers

TRENDING


Trending indicates a topic that is getting more attention than usual; trends are reported globally and regionally

POST


Formerly tweet. Historically have been short-form but can now be longer for paid users

PLATFORM	FEATURES	PROS	CONS
 Facebook	<ul style="list-style-type: none"> • Connect with friends/family • Share photos, videos, posts • Facebook Groups: lets users join interest-based communities 	<ul style="list-style-type: none"> • High opportunity for your content to reach a larger audience on a global scale 	<ul style="list-style-type: none"> • Organic visibility declined, growing an audience means paying for ads • Less favored amongst the younger audience


Tip: Facebook is a great platform for you to start an online support group

 Instagram	<ul style="list-style-type: none"> • Visual focused (pictures and videos) • Instagram stories: Posts that disappear after 24 hours that are used to have more personal engagement with your followers • Instagram reels: short form videos 	<ul style="list-style-type: none"> • Supports organic growth • Filters and editing tools in the app • High rate of engagement 	<ul style="list-style-type: none"> • Algorithm changes frequently • Must post very consistent to stay relevant • Not link friendly: can't put clickable links in your posts which negatively affects your SEO
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Tip: Instagram reels are great for engagement and exposure; focus on engagement rather than follower count


PLATFORM	FEATURES	PROS	CONS
	<ul style="list-style-type: none"> • Crowdsources important news and discussion threads • A medium to communicate and voice thoughts/ opinions on trending topics • Real time updates: posts (formerly tweet) are shown in reverse chronological order, a handy tool for keeping up with news and events as they happen • Twitter polls: invite your audience to participate and share opinions 	<ul style="list-style-type: none"> • Easily communicate and engage with followers • Tweet polls encourage interaction and increase engagement 	<ul style="list-style-type: none"> • New X update skews the algorithm to favor verified accounts (pay monthly for a blue checkmark) • Verified accounts get more features than free accounts (like more characters per post) • Too many hashtags can hurt your engagement

Tip: You can get in contact with notable companies, brands, and public figures by tagging them in the post and creating a more direct conversation.

PLATFORM	FEATURES	PROS	CONS
	<ul style="list-style-type: none"> • Business connections: Join organizations relating to their field and connect with coworkers, clients, and business partners • Recruitment and job searching • Networking site for users with a business profile • Great for building connections with other professionals or potential partnerships 	<ul style="list-style-type: none"> • Audience reach is a lot higher due to being more professional and less personal • Business exposure outside of your immediate network • LinkedIn profiles can improve SEO rankings for small business which comes across as more legitimate 	<ul style="list-style-type: none"> • Hard to reach younger audiences • Spam messages from many bot accounts

Tip: Use LinkedIn to highlight pivotal moments, accomplishments, and goals in your career and personal life.

PLATFORM	FEATURES	PROS	CONS
	<ul style="list-style-type: none"> Longer form videos such as movies, online tv-shows and more Latest feature: YouTube Shorts (Similar to IG Reels or TikToks) Thumbnails and hashtags to encourage viewers to click and watch 	<ul style="list-style-type: none"> High potential for large audience reach Partner with influencers and channels with a lot of subscribers is a great way to utilize a large audience Posting on YouTube helps your SEO ranking (as Google owns Youtube) 	<ul style="list-style-type: none"> Content and user oversaturation YouTube's algorithm cannot be heavily relied on for your content to get views (you have to promote your videos yourself) Strict censorship and restrictions can limit your creative freedom
<p>Tip: Use YouTube to share longer form videos that educates or inspire viewers</p>			

	<ul style="list-style-type: none"> 15 seconds-3 minute video based content Gives you the opportunity to get involved with trending content More laid back community to make informal content (highly appealing to younger audiences) 	<ul style="list-style-type: none"> High volume of traffic and exposure In app editing that allows you to customize filters, captions, and music to accompany your videos 	<ul style="list-style-type: none"> TikTok content might not align with the message your brand tries to deliver Trending content is more appealing than sticking with a cohesive theme like other platforms Advertisements can be very expensive
<p>Tip: TikTok is best used for informal and casual videos</p>			

Appendix C:

Health Insurance

Types of U.S. Health Insurance Plans

EXCLUSIVE PROVIDER ORGANIZATION (EPO)

Only covers in-network providers but usually has a larger network than an HMO with premium levels that tend to range between HMOs and PPOs

HEALTH MAINTENANCE ORGANIZATION (HMO)

Low-cost insurance with fixed copays, but members must choose doctors within the network and need referrals to see specialists.

HIGH DEDUCTIBLE HEALTH PLAN (HDHP) WITH HEALTH SAVINGS ACCOUNT (HSA)

Low premiums but higher out-of-pocket costs. HSAs allow pre-tax dollars for medical expenses.

MEDICARE

A taxpayer-funded program for seniors 65 and older and certain other cases (disability, end-stage renal disease, or ALS), with four parts (A, B, C, D) covering hospital stays, doctor visits, drugs, and more. Enrollees share costs through premiums and out-of-pocket expenses.

MEDICAID

A U.S. federal and state program assisting low-income patients with medical expenses. Funding varies by state, and eligibility rules differ across the 50 Medicaid programs.

PREFERRED PROVIDER ORGANIZATION (PPO)

More flexibility with higher premiums, allowing in-network and out-of-network doctors, though at higher rates for out-of-network care.

POINT OF SERVICE (POS)

Requires referrals from a primary care provider for specialists but covers out-of-network providers at a higher cost.

Important Terms to Know

CAPITATION

A limit on the total amount insurance pays for health services over a specified period (e.g., per year or lifetime)

COPAY

A fixed amount an insured person pays for a healthcare service, even when covered by insurance (e.g. you pay \$20 per physical while insurance covers the rest)

COINSURANCE

The percentage of healthcare costs you continue to pay after meeting your deductible (you pay 15% of the cost, and insurance covers the remaining 85%)

COVERED SERVICE

Healthcare services that insurance pays for according to the plan's coverage

DEDUCTIBLE

The amount you must pay out-of-pocket each year before the insurance plan starts covering expenses

PREMIUM

The fixed monthly (or yearly) payment for insurance coverage, separate from deductible, copay, and coinsurance

PRIOR AUTHORIZATION

Approval from the health plan that is required for certain services before a healthcare service is covered for a specific patient

Appendix D:

Policy Glossary

A

ABSENTEE BALLOT

A vote cast by someone who is unable to visit the official polling place on Election Day. This type of vote is normally submitted by mail. Increasing the ease of access to absentee ballots is seen by many as one way to improve voter turnout, though some jurisdictions require that a valid reason, such as sickness or travel, be given before a voter can vote with an absentee ballot.

ACT OF PARLIAMENT

A bill in the United Kingdom that has completed the legislative process (approved by House of Commons and House of Lords and has passed Royal Assent) and is approved to become law or change an existing law

ACT

A specific piece of legislation passed into law that pertains to a specific situation

ACTION CODE

Action Codes identify stages that condense detailed legislative action steps

ACTS OF PARLIAMENT

A law made by Parliament in the United Kingdom

AMENDMENT

A modification to the text of legislation

APPORTIONMENT

Establishment of legislative districts for elections and the census

APPROPRIATION

Funds allocated for various government departments

AT-LARGE ELECTION

Candidates represent the entire population such as a city, county, or country instead of a single district. In the U.S. States with smaller populations practice at-large elections.

B

BICAMERAL

A legislative branch with two houses, both checking the other's power. The U.S. has a bicameral legislature consisting of the Senate and the House of Representatives.

BIENNIUM

A two-year period of legislative activity

BILL

A draft of a law presented to a legislature for enactment. If the legislature passes the bill, the draft becomes law.

BIPARTISAN

Affiliation with the representatives of both U.S. political parties or the political parties themselves

C

CABINET

The main advisory body for the President of the United States, consisting of the Vice President and the heads of 15 executive departments

CARRY-OVER LEGISLATION

Legislation that is held from the first year of a legislative biennium to the second year

CAUCUS

A meeting of members, typically from the same political party but could be on the basis of gender, race, or geographic location

CENSURE

An official reprehension by a legislative body to an elected official for inappropriate actions while in office

CHAIR

A presiding officer of a group, such as a committee

CHAMBER

Official room for the meeting of a legislative body. The U.S. Senate and House of Representatives chambers are on opposite ends of the Capitol building.

CHECKS AND BALANCES

Separation of powers to allow different branches to check each other's power to keep the balance of government. In the U.S., the judicial, legislative, and executive branches check one another in multiple ways.

CLOTURE

When 60 out of 100 senators agree to end a filibuster or a hold

COMMITTEE OF THE WHOLE

An entire legislative house sitting as a committee to consider bills or subjects

COMMITTEE

A smaller group of legislators delegated by a legislative body to consider and report on a specific topic. Having multiple committees allows for quicker and simultaneous completion of legislative work. Committees often analyze the implications and effect of a bill and provide a recommendation to the entire Congress. U.S. federal and state legislatures have many committees such as the Health, Education, Labor, and Pensions Committee and the Agriculture, Nutrition, and Forestry Committee.

CONFERENCE COMMITTEE

In the U.S., a committee appointed to reconcile the different versions of a bill

CONFIRMATION

Approval by the Senate of gubernatorial or presidential appointments

CONGRESS

The lawmaking body of a nation. The U.S. Congress is a bicameral legislature and consists of publicly elected representatives in the House of Representatives and Senate. Both the House and the Senate need to pass a bill to send to the President for confederation.

CONGRESSIONAL BRIEFING

Meetings held by people who brief Congress on a specific topic to inform their vote on related legislation. Although Representatives and Senators do not attend most congressional briefings, Capitol Hill staffers do and report back.

CONGRESSIONAL BUDGET OFFICE (CBO)

A federal agency within the U.S. legislative branch that reports budget and economic information to Congress

CONSTITUENT

A citizen that resides within the elected legislator's district

CONSTITUTION

A document outlining a body's fundamental principles, the rights of the people, and the powers and duties of the government

COUNCIL OF THE EU

Also Council of Ministers; part of the legislative branch consisting of 28 national ministers in charge of approving or rejecting proposed legislation

COUNCIL

A body of people elected to vote on and manage the affairs of a city, county, or other municipal district

COURT OF JUSTICE OF THE EU

Part of the judicial branch of the EU in charge of interpreting law and settling disputes over law; consists of two courts in which judges are appointed jointly by national governments

D

DEMONSTRATION

A mass expression of public sentiments, such as a protest

DISSENT

A negative vote or a difference of opinion, particularly in judicial rulings of a court

DISTRICT

The separation of a state into multiple districts. Each district is represented by an elected legislator.

E**ELECTION**

Selecting a person to fill an office through popular vote

ELECTORAL COLLEGE

A body of appointed representatives who vote for a particular party's candidate. In the U.S., the Electoral College formally elects the President and Vice President.

ELECTORAL COLLEGE

Present in the U.S. election for president and vice president. The population votes for appointed representatives, electors, to vote for a particular party's candidate.

ENACTED

When a bill is made into a law

ENGROSS

The process of updating a bill while it is in the Senate or the House of Representatives

ENROLL

Modifying a bill that was passed by houses into its final format

EUROPEAN CENTRAL BANK

Maintains the stability of the euro and oversees European financial system as a whole, consisting of a President and executive board appointed by the European Council

EUROPEAN COMMISSION

Part of the executive branch that proposes and implements legislation, consisting of 28 commissioners that are nominated by the European Council and approved by Parliament

EUROPEAN COUNCIL

Part of the executive branch of the EU that sets the policy agenda to be addressed and consists of the heads of state or government of the 27 EU member states, the European Council President and the President of the European Commission

EUROPEAN COURT OF AUDITORS

Part of the judicial branch that consists of 27 members appointed by the Council of Ministers, in charge of auditing the budget

EUROPEAN PARLIAMENT

Part of the legislative branch, consisting of members that are directly elected by EU citizens that approve or reject proposed legislation

EUROPEAN UNION

A political and economic union of 27 European member countries

EXECUTIVE BRANCH

The executive branch of the government is responsible for executing and enforcing a country's laws. In the U.S., the executive branch is made up of the President, their cabinet, and various government departments.

EXECUTIVE ORDER

A command for the governor or president to the executive branch that was not voted on by the legislature

EXECUTIVE SESSION

A portion of the U.S. Senate assembling to delegate on treaties, federal executive officials nominations, and other items introduced by the President

EXPUNGE

The removal of specific portions that may be objectionable or incorrect from the journal/record

F

FEDERAL REGISTER

A daily publication of U.S. federal government's proposed rules, accepted rules, and public notices; think of it as the "newspaper" of the federal government

FEDERAL

In the U.S., includes legislative, executive, and judicial branches that represent all 50 states, the District of Columbia, and its territories

FILIBUSTER

An extended debate given by one or more members of the legislature to delay or prevent a vote on a bill

H

HEARING

A public discussion on a bill, usually organized by a congressional committee

HOLD

U.S. Senator(s) prevent a motion from reaching the Senate floor. If the Senator(s) privately request a hold from their party leadership, it is called an anonymous or secret hold.

HOUSE OF COMMONS, CANADA

The lower chamber of Parliament consisting of one member from each electoral district

HOUSE OF COMMONS, UNITED KINGDOM

The lower house of Parliament in the United Kingdom consisting of the Prime Minister and 1 member for each region of England, Scotland, Wales, and Northern Ireland

HOUSE OF LORDS, UNITED KINGDOM

The upper house of Parliament in the United Kingdom where membership is granted by appointment or hereditary right

HOUSE

A lawmaking assembly. The U.S. House of Representatives is the larger of the two chambers in the U.S. Congress. A fixed number of 435 representatives are elected from their own congressional districts across the 50 states. Congressional districts are organized by population, whereas California has 53 congressional districts and 53 representatives, states such as Alaska and Vermont have only one representative.



IMPEACHMENT

Procedure to remove a public official from office due to possible misconduct

INTERIM COMMITTEE

A committee to examine a topic between legislative sessions to report in the next session

INTERIM

The interval between legislative sessions



JOINT COMMISSION

An independent, not-for-profit group in the U.S. that administers voluntary accreditation programs for hospitals and other healthcare organizations

JOURNAL

An official chronological record of the actions taken in a chamber

JUDICIAL BRANCH

In the U.S., the judicial branch is made up of the Supreme Court, which interprets the U.S. Constitution

JURISDICTION

The official power to make legal decisions and judgements



LAW

A general system of rules a city, county, or country acknowledges that regulates behavior and may be enforced with penalties

LEGISLATION

The act of making or enacting laws, or the proposed or passed law

LEGISLATIVE BRANCH

The U.S. legislative branch is made up of the House and the Senate. The legislative branch has several powers, including making laws and declaring war.

LEGISLATOR

An elected member to serve in a legislative body

LEGISLATURE

A body that, in the U.S., is elected to deliberate, create, modify, or repeal the laws for the city, county, or country it represents

LINE ITEM VETO

A veto of a specific item in a bill

LOBBY

The act of persuading legislators to introduce or vote for measures in their interest

LOCAL GOVERNMENT

Cities, counties, and municipalities have local governments that regulate and enforce laws that only apply within the specific region. Local governments have city councils which are the governing body. If a local law conflicts with a state law, the state law supersedes.

M

MAJORITY

A voting method that elects the candidate that receives the majority of the votes, or more than 50 percent

MARKUP

The process of making final changes in a legislative bill

MEASURE

A general term for a bill, memorial, or resolution

MEMBER OF PARLIAMENT

A person elected by their constituency in the House of Commons

MONARCH

A person who rules over a kingdom or empire, such as the King of England

MOTION

A proposal from a legislative member that the Senate or House should take a certain action. Common motions are adjourning a session or voting on a measure

N

NON-GOVERNMENTAL ORGANIZATION (NGO)

An organization that operates independently of any government, often not-for-profit

NONPARTISAN

Having no affiliation with representatives or either major political party

O

OFFICIAL TITLE

A concise statement of the subject and the contents of a bill

OPEN SESSION

The condition when Congress convenes and the session is open to the public

ORIGINAL BILL

A bill before amendments are made in Congress

P

PARLIAMENT

A governing body whose members make and/or change legislation, existing in the UK and Canada, similar to Congress in the U.S. In the United Kingdom, Parliament is made up of the Crown, the House of Lords, and the House of Commons.

PARTY

A group of people with similar political goals and opinions that work to get candidates from their party elected into public office. For example, the Democrat and Republican parties are the two main political parties in the U.S.

PATRON

The person who presents a bill for consideration

PETITION

A formal request submitted by an individual or a group to the legislature. Common petitions include proposals to create, change, or vote on a law.

PLURALITY

A voting method that elects the candidate that receives that most votes; the candidate does not necessarily need to have the majority vote.

POLICY

An overall plan, principle, or guideline pursued by an organization

PRIMARY

A preliminary election in which voters elect a couple of party nominations for the general election. Most states require an official party affiliate in order to vote in a primary election.

PRIME MINISTER

The head of the cabinet and leader of government ministers in the executive branch, most notably in the UK and Canada

PRO TEMPORE

A designated officer acting in the absence of the presiding officer

PROCLAMATION

An official declaration to make an issue known. Presidential proclamations are policy announcements from the president.

**QUORUM**

A majority of members of the group described

**RANKING MEMBER**

The second-most senior member of a committee from the majority party

RATIFY

To approve

REAPPORTIONMENT

Redrawing legislative district boundaries to provide better equality of representation

RECALL

The public calling for a trial on an elected official to be removed from office

REFERENDUM

Recently passed legislation by the legislature referred to the voters. The voters can vote to enact or reject the referendum.

REPEAL

When a legislative action is revoked

ROYAL ASSENT

The method by which a monarch formally approves legislation to then become law or change an existing law

S

SELECT COMMITTEE

An often temporary committee organized for a specific purpose

SENATE, CANADA

The lower house of Parliament where members are appointed by the Prime Minister

SENATE

A lawmaking assembly. The U.S. Senate is the smaller of the two chambers in the U.S. Congress. Each state elects two senators to represent the entire state and have unique powers that the House of Representatives does not have such as ratification of treaties and the confirmation of federal executive officials.

SPEAKER

The title of the elected presiding officer of the House of Representatives. Some states use this title for its Senate chamber as well.

SPECIAL ORDER

To set consideration of a bill for a specific, later time

SPECIAL SESSION

A meeting of the legislature called by the legislature, governor, or president to discuss specific matters

SPONSOR

A legislator who introduces a bill or resolution and can be joined by other legislators, known as cosponsors

STANDING COMMITTEE

A permanent committee that meets regularly

STATE

Typically, state governments mirror the federal government, its governing bodies consist of legislative, executive, and judicial branches instead of a city council. If a state law conflicts with a federal law, the federal law supersedes.

STATUTE

The laws of a country that are passed by the legislative body

SUBCOMMITTEE

Congressional subcommittees typically consist of half the members or less than the committee it is a part of and are assigned to review a specific topic and report back to the full committee. For example, the U.S. Senate Health, Education, Labor and Pensions Committee has a Subcommittee on Children and Families. Subcommittees play a vital role, and committees refer most bills Congress votes on to subcommittees.

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T

TENURE

The period of time or term during which an office has been held

TREATY BODY

A committee of independent experts brought together to oversee international treaties

TREATY

Otherwise known as a convention or covenant. According to International Law, a treaty is a legally ratified agreement.

U

Unicameral

Describes a legislative body with only one house, example being the state of Nebraska

V

VETO

In the federal government, an action by the President to disagree with the approval of a measure

VETO OVERRIDE

The legislature voting to pass a bill despite the governor or president's veto

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Global Liver Institute (GLI) is a patient-driven 501(c)(3) nonprofit organization headquartered in Washington, DC, with offices in the EU and UK, founded in the belief that liver health must take its place on the global public health agenda commensurate with the prevalence and impact of liver disease and the importance of liver health to well-being. GLI promotes innovation, encourages collaboration, and supports the scaling of optimal approaches to improve research, care, and policy. By bringing together more than 200 community-based, national, and international organizations across its Councils, Campaigns, and events, GLI equips advocates to identify and solve the problems that matter to liver patients. Follow GLI on Twitter, Facebook, Instagram, LinkedIn, and YouTube.

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The background of the entire page is a light blue gradient. Overlaid on this are several dark blue silhouettes of graduation caps (mortarboards) floating in the air. At the bottom of the page, there are silhouettes of a group of people, some wearing caps, with their arms raised in celebration. One person on the right is holding a rolled-up diploma high in the air.

It all starts with a patient

Learn more



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