Kelly Greening (00:04)
Ask what's required versus optional. Ask who will see your information that you're providing. And just remember that asking questions is part of being an informed patient, not a difficult one.

Priya Bathija (00:19)
In America, sometimes it seems like we're plagued by forms. Found a new doctor? Here are seven forms to fill out before your appointment. That doctor sends you for imaging? More forms! And some of these are the same forms you already filled out. Months later, you need a different kind of imaging with the same company. Thank goodness. Nope. It's at their other location in town, so more forms. They have an online portal. And sign up requires, you guessed it, filling out more forms.

Worst of all, you're checking off boxes, you're detailing your arm break from 15 years ago, you're listing your next of kin for the 12th time, and you're making judgment calls about what and how much to share when you really aren't sure what they actually mean. And to top all of it off, you're frustrated because you're going to have to repeat it all again when you see your doctor. It's easy to get absolutely buried in paperwork when all you wanted to do was talk to your doctor, or get more information about your health.

Priya Bathija, and this is the Women's Health Playbook. Together, we're going to make healthcare just a little bit easier. Because right now, navigating the U.S. healthcare system, especially as a woman, is like playing a game. Except you don't know the rules. The instructions are written in a language you don't speak, and the stakes are your life.

Today's play, we're sorting through the forms. What are they for? How much should you share? What do do if you feel uncomfortable answering a question on a form? Is your data even safe? Let's get your documents in order as we head behind the clipboard and master that paperwork.

Our coach for today is Kelly Greening.

Kelly Greening (02:25)
I'm Vice President and Deputy General Counsel at Ann and Robert H. Lurie Children's Hospital here in Chicago.

Priya Bathija (02:32)
Kelly's practice focuses on data privacy and security, digital health, AI, fraud and abuse, and many other areas.

Kelly Greening (02:41)
And I also have a personal focus on an incredibly important topic of health equity. And I'll state that I think women and children really experience the health system at its most vulnerable points. And the inequities that they experience create avoidable harm with lifelong consequences.

Priya Bathija (02:59)
And for this reason, Kelly says she spends a lot of time thinking about the patient experience and how best to navigate the health system.

In this interview, Kelly walks us through a breakdown of the standard paperwork you'll need to fill out before an appointment, including what the forms mean and who they are for, plus everything from using patient portals and understanding data access to why you should create your own personal health record.

I'm excited to drill down and really highlight for those that are listening, like why we have all these forms and what they need to know about them before they sign on the dotted line. So can you start with breaking down what some of the standard paperwork is that patients are asked to complete when they show up at their doctor's office?

Kelly Greening (03:54)
Yeah, of course. And it's such an important question. These are not throwaway documents. Each one has a different purpose and each is really important. So you'll often see patient intake forms and medical history questionnaires. You'll see a notice of privacy practices, a general consent to treat, often financial responsibility agreements, including for nonprofit hospitals, for example.

a notice of financial assistance that might be available that's required by law. And in some cases, a financial needs assessment or a social influencers assessment. ~ If you'd like, I can just go in order and start with the patient intake and medical history questionnaires.

Priya Bathija (04:38)
Yeah, that would be great. Tell us what each of these forms does, why they're important, and what we need to know about them.

Kelly Greening (04:46)
Sure. So the intake forms collect really basic identifying information and insurance details, but often will also ask about race or ethnicity, language preference, gender identity, even sometimes sexual orientation. And these questions are really typically used to improve care, sometimes meet some public health reporting requirements and identify some potential

disparities. This isn't to determine eligibility for care. It's so your doctor can be more educated about who you are. Most of those demographic questions are optional, and patients should feel empowered to ask which ones are required if they're uncomfortable answering any of those questions. One practical tip, though, is that incorrect demographic information can really follow you across multiple health systems. So it's worth reviewing carefully and answering honestly. And if you don't feel comfortable answering a question, that's generally fine too.

Priya Bathija (05:48)

You mentioned that there may be information that patients are uncomfortable sharing and that they could ask the question about which is actually needed and what is not needed. Is there approach you give or advice you give to patients who want to raise that question?

Kelly Greening (06:04)
My advice is to either just leave it blank and see if they are coming back and asking you to fill it out, or you can raise it once you're in the room with the provider and say, hey, I'm a little bit uncomfortable answering this question. Can you tell me, and this is a common theme I'm gonna come back to, how you plan to use or share this information? This is something that you should always feel really comfortable asking in the healthcare space. There are laws that will go over. Talk about and govern how information can be shared in the healthcare system. But you as the patient are the consumer and you have the right and frankly responsibility to ask those questions if you have a discomfort with sharing anything in particular.

Priya Bathija (06:49)
Great, thanks. Okay, on to the next form.

Kelly Greening (06:52)
So the medical history forms, these are pretty straightforward and standard, but they do directly affect your clinical care. So medications, mental health history, pregnancy history, allergies, prior diagnoses, these all matter. And once again, I'll state, if you're unsure why something's being asked, it's absolutely okay to ask, but accuracy and honesty are really important for patient safety. The next form I can turn to is the notice of

privacy practices, and this is a really important one, but it's actually not a consent form. It's a disclosure. So when you sign it, you're acknowledging that you've received information explaining how your health data can be used and what rights you have under federal law in relation to that data, specifically HIPAA. So HIPAA is a word that almost everyone's heard of, but many don't really understand

the ins and outs of this law. And I won't spend our time getting into all the details of HIPAA, but I will share some general overview important notes, which is HIPAA limits how protected health information, which we call PHI, like a diagnosis or a lab result or visit notes can be used or shared by the providers. So why is this worth reading? It tells you how your provider can use and share your data.

There's a common misconception that any sharing of my health data without my express consent is a HIPAA violation. But in reality, providers can share without your permission for what we call TPO, treatment, payment, and healthcare operations. They can send your claims data to an insurance company for billing. Makes sense, right? They can send it to another provider for co-treatment purposes.

That's all okay under the law and the notice of privacy practices lays that out. But it also explains the patient's rights with respect to their data. HIPAA gives patients rights to access their records, to request corrections of information in their record that they believe is inaccurate, and to file complaints if they think that their privacy has been violated.

Priya Bathija (09:13)
So that's an important one to read, right? That's typically the one I don't read.

Kelly Greening (09:18)
It is an important one to read because I think that there can be a misconception that your providers aren't going to share your information under any circumstances, but there are reasons that are appropriate under HIPAA to share your information. So reading that, understanding that, and feeling free to ask questions of your provider about the boundaries of their data sharing practices is fully within the rights of a patient who's seeing the doctor.

Priya Bathija (09:48)
That's great. And you also mentioned financial forms and financial policies. Can you dive into those?

Kelly Greening (09:54)
Yeah, of course. So these forms generally explain that patients are responsible for charges not covered by insurance. They can include billing policies and collections language, but also financial assistance information. And patients can and should ask about payment plans, financial assistance early on in their care if they believe that they might be eligible.

And nonprofit hospitals, I think I alluded to this earlier, are required under federal and often state law to provide a financial assistance policy and a plain language summary of that policy. So it's not just gibberish legalese, it's explaining in clear terms what financial assistance is available, to who, and how to apply under the hospital's policy.

Priya Bathija (10:47)
What if they don't provide that to a patient? What's the best way to access it?

Kelly Greening (10:51)
It needs to be available on the hospital's website. It also should be in plain sight in the hospital waiting areas. And if it's not, they should feel free to ask for that policy and the plain language version at the front desk. And also feel free to note that it should be available more readily than they've experienced it to be.

The other financial related form that we talked about earlier briefly is a non-medical social needs assessment. So this is often a separate form and instead of just informing all patients about policies around financial assistance, it will ask questions about the patient family's income and housing, access to healthy food, transportation, safety. It's really meant to identify barriers to care and help the institution or physician connect patients to resources that can be helpful to that patient. There's also some anti-patient bribery laws that prohibit doctors and practices from providing free or discounted items to patient families, but there's an exception to those laws for patients with demonstrable financial needs. There's additional criteria around that exception like what's provided needs to be related to patient care, but it's an important tool where physicians and practices can provide help to patient families around their social influencers of health and not just their diagnoses, right? So food insecurity, for example, a provider may be able to provide fresh, healthy food in a food pantry. So again, when filling out these forms, it's important to be accurate, but patients… can and should also feel free to ask, is this information going to be protected? Is this information going out the door in any capacity? And not fill out the form if they don't feel comfortable.

Priya Bathija (12:55)
I appreciate you calling out the fact that they shouldn't fill out the form if they don't feel comfortable. Because I know in many situations, it may feel very uncomfortable to share this non-medical social needs information. Like, for example, I may not want to share that I don't have access to food or that we don't have secure housing because it may impact my kids in the long run or may impact me. so

How do you try to get over that barrier with patients so that they do feel comfortable sharing that information?

Kelly Greening (13:30)
I think it's really critical to share the why of why it is that you're asking for that information. It's not to pass it on to anyone else. It's to help if there's help that can be available. Lurie Children's, for example, really engages in a lot of care coordination activity, and we try to provide a lot of resources to patient families that can benefit from them. But we're limited in terms of what we can offer if we don't know what a patient family needs.

There's also a trust, I think, that needs to be built up. And oftentimes, a patient's family might not initially feel comfortable, but might after developing trust with the provider feel more comfortable filling out those forms and having more of an open dialogue with a social worker or otherwise. These also are forms that are kept not necessarily with the front desk, but are relayed through a social worker. So there's some kind of more confidential treatment of that information.

Priya Bathija (14:33)
So is there anything else about these forms that you think we need to cover?

Kelly Greening (14:40)
One of the forms that we didn't cover that's a really basic one, but an important one that you'll definitely get is a general consent to treat. So this is just a consent to create a patient-doctor relationship and to give you general care. It's consent for the clinician to evaluate you, diagnose you, and provide treatment. Non-routine care, though, will require an informed consent form, which is specific to that.

non-routine procedure or medication. But the consent to treat will acknowledge that medical care involves risks and uncertainties. will consent for emergency care if the patient can't respond. If you're in a teaching hospital, it will acknowledge that trainees might be involved in your care. It could be a consent for routine clinical photography or documentation.

And another concept you might see on that form is actually the agreement to share your electronic health information through data sharing programs to other providers. So for example, I'm a patient of Dr. A and Dr. A documents in my electronic medical record that I'm allergic to a particular medication. I then travel out of state and I'm in a serious accident and I'm taken to the ER.

Dr. B is treating me there. Dr. B and Dr. A don't know each other. I'm not conscious, so I can't provide any information. Data sharing programs might allow Dr. B to query the electronic medical database for my records in my home state. Then Dr. B sees, I'm allergic to that medication. They're not going to give it to me. So that kind of interoperability is the word ~ that's used to describe that. It's something that the federal government really supports as helpful to patient care, as do a lot of advocacy groups. But patients can usually opt out if they're not comfortable with their records being queryable.

Priya Bathija (16:39)
That's really helpful and I never knew that that existed and that if you were to be in that situation that your treating physician could have access to additional information about you to make sure that they are treating you in a safe and effective way. So that's really great to know.

Hey, it's Priya. I just wanted to pop in here and encourage you to send this episode to a friend. The information we're sharing here is so valuable, and it's how we help each other get the best care possible as women in America. So hit the share button on whatever app you're listening on. Send it to your daughter, sister, aunt, mother, a coworker, or honestly, send it to every girl dad you know, because the more we all know, the better healthcare will be for everyone. Okay.

Back to the play. Another thing that we're often asked to sign up for or sign on to when we are at a doctor's office is a patient portal. Can you tell us more about sort of what a patient portal is and how it can be used effectively to improve sort of your experience and your outcomes in your care?

Kelly Greening (17:51)
Yes, patient portals are incredibly important and are only being used more and more in healthcare. So they're online platforms that give patients access to their own medical information, often in real time. Test results, even visit notes, patients can use them to schedule appointments and to pay bills and engage in secure messaging with their providers. So this is a tool that can be really empowering.

but there are also some areas that can be a little bit confusing or even off-putting. And one piece I think it's important to acknowledge is that some patients are surprised when test results might appear almost immediately prior to receiving a call from a provider. This access is really powerful, but also can be unnerving if you're seeing a test result without having a provider explain it to you.

And that's because of a federal law called the Cures Act, the 21st Century Cures Act. And this law, without going into a bunch of detail, really requires health systems and providers to share test results and clinical notes with patients without any unnecessary delay. The goal is transparency and patient empowerment, but the downside is that patients may at times see results before the clinician has had the chance to explain them, and that can feel stressful.

So in that case, it is absolutely okay and important to reach out to the clinician, use that secure messaging, call the office, whatever feels more comfortable for you, and ask for clarification of what you're seeing on the patient portal. The other piece I wanna mention on a patient portal is something called proxy access. Proxy access means giving someone else permission to access your data in your portal.

So for adults, that could be a spouse, it could be a caregiver, ~ it could be an adult child. For children, it's usually a parent or a guardian. And it's granted really intentionally in an oftentimes limited ways depending on age or state law. So in the pediatric context, for example, and this is important for your listeners who are parents, proxy access changes over time.

from the ages of zero to 11, a parent will have full proxy access to their child's patient portal. At the age of 12 or as children become adolescents, privacy laws at the state level will limit what parents are allowed to see, especially around reproductive health, mental health, substance abuse, and so they will have a limited proxy access to their child's chart.

That's not the entity hiding information. That's not the doctor coming between you and your child. It's the law protecting teen privacy. And those laws do differ by state. So I'm speaking from the Illinois perspective, but pretty much every state has adolescent privacy laws that can be, that can impact access in a patient portal.

Priya Bathija (21:05)
Okay, so you just taught me a lot that I never knew, which I love. And I have always wondered why test results are dropped into the portal before clinicians had a chance to go over them with patients. And I've actually thought, why aren't we advocating that the phone call comes first and then the information is pushed after? And I never knew that it was because of a law and the 20th Century Cures Act that required that.

Kelly Greening (21:31)
A lot of clinicians agree with you, Priya, and wish that we could hold those test results back. But unfortunately, for the most part, with some exception, the Cures Act does require that they go without any unnecessary delay. Without nerding out too much, there is an exception for preventing harm. So if there's a test result that sharing would cause harm without a provider explanation, they may be able to use that exception.

to hold the test result back until they're able to have that discussion. But again, that's an exception, not the rule.

Priya Bathija (22:05)
Yeah, thank you so much for breaking that down. I have several doctors all in different health systems. I am part of many portals. I have information at a lot of different doctors' offices. How can you, as a woman, create a digital trail across all of these systems? So how can you make sure that you know where your stuff is and that you can present it to future clinicians when you meet with them?

Kelly Greening (22:34)
I love that question. I think it's really important to create your own simple health record that's separate from any hospital or portal system because portals are really helpful. But as you mentioned, they don't always talk to each other. Access can change over time. You can change providers. A practice might shut down. So I would recommend keeping a personal digital health binder that you control. And that can just be really simple, like noting

dates, providers, facilities, so you have a really clear timeline of your care history. ~ Downloading your key test results and imaging reports, they're often provided to you in a downloadable form or if not screenshot. Saving your visit summaries, your ~ discharge instructions if you're inpatient, and really importantly, keeping a running list of diagnoses and medications and of course, allergies.

You know, it doesn't have to be fancy, but it should be secure. So I would definitely advise that we password protect these digital health binders. But the goal is really continuity. Having your own record makes it easier to advocate for yourself and to catch errors in your record and navigate care, especially when you're seeing multiple providers.

Priya Bathija (23:54)
Yeah, no, that's great. And I think it's great that you mentioned screenshots. I was actually at an OB-GYN appointment and they wanted to know what my latest blood results were from my primary care physician. And I forgot to download that in advance of the appointment, but I like quickly got on the portal for my primary care physician, screenshotted all the numbers and was able to give that to my OB-GYN. So it...

We don't have to over complicate it, but we do need to encrypt and protect it, because that screenshot was very much not protected.

Kelly Greening (24:28)
Right, I fully agree.

Priya Bathija (24:31)

What sort of high level tips do you have for women who are completing these forms and navigating patient portals? Like, what should they know? Top line.

Kelly Greening (24:43)
Yeah, I often think of this in terms of women as parents as well. So I hope you don't mind I bring that perspective because I'm working in a children's hospital, but I think moms are often the chief medical officers for their kids. I certainly am. They're managing appointments and portals, finances, consent forms, insurance, school requirements and school forms. So it's just really important to

feel empowered and educate yourself so you can get better at navigating this healthcare system and get the care and support that you and your family need. I think a great example is financial assistance. Read those forms. These programs exist to help, and you can see if you qualify. Some other practical takeaways. Ask what's required versus optional. Ask who will see your information that you're providing. Keep digital copies of key documents.

Secure your portal access. I think you mentioned ensuring that you have a strong password that's really important to factor identification if possible. Just remember that asking questions is part of being an informed patient, not a difficult one. I think women sometimes, certainly myself in prior years, ~ can feel nervous about being difficult and

You should not feel that way. This is your health. It is important that you ask questions and that you are educated and empowered to do so.

Priya Bathija (26:20)
Yeah, and I think we'll cover in other episodes within this play of navigating your doctor's visit. If your clinicians or the care team that you're meeting with aren't willing or able to answer these questions, you need to dive a little deeper to make sure that you can get that information. And in some cases, it may mean you don't have the right doctor that aligns with your care needs and what you're doing. And so

I think it's really important what you just said that this isn't something we should be afraid of. We should be having these conversations because these are really important pieces of information that impact how healthy we are.

Kelly Greening (27:02)
and have impacts for years to come.

Priya Bathija (27:05)
Kelly, thank you so much for being with us today and for breaking down all of these forms and stacks of paper that we get when we are at a doctor's appointment. So thank you again for being with us. And that's a wrap on this episode of the Women's Health Playbook.

Kelly Greening (27:23)

Thank you so much.

Priya Bathija (27:33)
Thank you for listening to the Women's Health Playbook. We hope this breakdown helps you receive better care as a woman in the United States. If you want to dive deeper into the tactics and resources we discussed today, you can find those in the show notes for this episode. The Women's Health Playbook is brought to you by Nyoo Health. That's my company. We help people and organizations reimagine how they prioritize and deliver care for women. For more information on the work we do, visit newhealth.com. That's N-Y-O-O ~ health.com. And for more plays you can use to take control of your health and healthcare journey, visit us at womenshealthplaybook.com. I'm Priya Bathija. Catch the next episode of the Women's Health Playbook right now in your favorite podcasting app. And we hope you'll share this episode with a friend because the more we all know, the better healthcare will be for everyone.