1

Patient Data Manager

Collect your health data for sharing with anyone you want.

An open source project by MITRE

Let's Get Started

Sign In

2

IT'S YOUR DATA.

WE JUST MANAGE IT. FOLLOW ME AS I EXPLAIN WHAT YOU CAN DO WITH THE PATIENT DATA MANAGER.

Next →

FEEDBACK: Mention that they are about to go through the Patient Data Use Agreement.

"Know your rights in 3 minutes through the Patient Data Use Agreement."

"In 3 minutes, know your rights from the Patient Data Use Agreement."

"In 3 minutes, understand the Patient Data Use Agreement."

3

YOU OWN YOUR HEALTH DATA. IT'S THAT SIMPLE.

HEALTH DATA

Next →

4

YOUR DATA CAN COME FROM ANYWHERE: FROM YOU, A CLINIC, OR A DEVICE. WE PUT IT ALL IN THE SAME PLACE.

Next →

5

NOW YOU CAN FINALLY HAVE ONE PLACE TO SEE YOUR ENTIRE HEALTH PICTURE.

Next →

FEEDBACK: Talk more about the "benefits" of the PDM. Help with your care.

How is this a visual to "my health", "my soul"?

6

MISTAKES HAPPEN. THIS IS WHY YOU CAN CORRECT AND COMMENT ON YOUR DATA.

Next →

FEEDBACK: We need a disclaimer in the PDUA that indicates changing/annotating data with PDM doesn't change it at the provider's office. Maybe it can – but I don't think we're offering that right now.

7

YOU CAN SHARE YOUR DATA WITH ANYONE. WE ALWAYS NEED YOUR PERMISSION BEFORE SHARING YOUR DATA.

Next →

FEEDBACK: Is there a contract for the receiver of any shared data?

8

YOU CAN SHARE YOUR DATA FOR RESEARCH. YOUR DATA CAN HELP RESEARCHERS LEARN MORE ABOUT HUMANS, AND DISCOVER NEW TREATMENTS.

Next →

FEEDBACK: Your data will help us...learn more about how to prevent and treat illness.

Prevent and treat illness is broader than cures, as most treatments aren't curative. I'm not sure if doesn't make the case as clearly though?

9

YOU CAN SHARE YOUR DATA AUTOMATICALLY DURING AN EMERGENCY. FIRST RESPONDERS WOULD BE ABLE TO SEE CRITICAL HEALTH INFORMATION ABOUT YOU.

IN CASE OF EMERGENCY

Next →

10

YOU CAN REVIEW WHO HAS ACCESS TO YOUR DATA.

Halfway through, continue →

FEEDBACK: Is this who can see your data or who sees your data or both?

Are we also able to detect if people have accessed shared data?

11

YOU CAN STOP SHARING YOUR DATA AT ANY TIME.

Next →

FEEDBACK: Is this person a little too angry looking?

12

HOWEVER, THOSE YOU HAVE SHARED WITH MAY KEEP A COPY OF YOUR DATA. BUT, THEY CANNOT GET ANY NEW DATA AFTER YOU STOP SHARING.

Next →

FEEDBACK: Who is they?

In screen 11, I'm a little tripped up by the use of "they". Screen 11 says that you can stop sharing, but it never actually says with whom, so "they" on screen 12 can't be directly resolved. It's an anaphor without a textual referent, and I think that's a bit confusing. One option would be to switch "they" to "those you shared with", but that might be too wordy.

Another small point on screen 12. I think "when" sounds a bit odd, and using "after" or "since" might be better.

13

YOU CAN DELETE YOUR DATA. WE WON'T KEEP A COPY. HOWEVER, WE CAN'T MAKE PEOPLE YOU HAVE SHARED YOUR DATA WITH DELETE THEIR COPIES.

POOF!

Next →

FEEDBACK: Just said they will keep a copy and then say we won't keep a copy? Will we need to keep a copy from legal standpoint?

Since in screen 12 we went out of our way to say that those you shared with may keep a copy of your data after you stop sharing, it seems a little inconsistent to imply that they can't by deleting your data (screen 13) or transferring your data (screen 15). It might be redundant to add that, but when I read "we won't keep a copy", I might mistakenly assume that "we" refers to not only the PDM, but other entities with whom I've shared my data through the PDM.

I believe the PDM's would keep a record copy for a while without additional aggregation (for legal protection or near term customer reversals).

14

YOU CAN TRANSFER YOUR DATA. WE WON'T KEEP A COPY.

Next →

FEEDBACK: Again, do we need to keep a copy from legal standpoint?

15

WE'RE RESPONSIBLE FOR KEEPING YOUR DATA SAFE. YOU CAN HOLD US ACCOUNTABLE IF THERE IS A DATA BREACH FROM THE PATIENT DATA MANAGER.

Next →

FEEDBACK: I think the jail pic gets the point across but is this optimal? I don't have a different suggestion though. Maybe a safe instead (more positive)?

I also agree with George that the jail picture gets the point across but might be too negative.

Data breach from which application?

16

IT'S YOUR DATA.

YOU ARE IN CONTROL.

Five steps left, continue →

17 SIGNATURE FOR PDUA

Signature

Type your full name to sign

☐ By checking this box, I understand and agree to the terms of the Patient Data Use Agreement and acknowledge that typing my name above represents my electronic signature.

Disagree | Agree

FEEDBACK: Can the user export a signed PDUA in PDF?

18 CREATE ACCOUNT

Get control of your health data!

Create your account with the Patient Data Manager.

Email

Password SHOW

Create Account

Person shall receive appropriate emails verifying their account and its status.

19 SETUP 2FA

Verify your phone number.

For security reasons, we want to make sure it's you. We'll send a text message with a code.

Phone number

Send Code

20 VERIFY 2FA

Confirm your identity.

Enter the code sent to your phone number ending in 5555.

Send code again

From Messages
451090

1 | 2 ABC | 3 DEF
4 GHI | 5 JKL | 6 MNO
7 PQRS | 8 TUV | 9 WXYZ
0

21 ACCOUNT CONFIRMED

Account created! Now let's connect your first source of health data.

On the next screen, you'll see the health data already on your phone using HealthKit. Select the data you want to own.

Next →

FEEDBACK: Should it go to HealthKit or somewhere else? What if running on web or Android? Can we present provider look-up from PDM?

22 HEALTHKIT ACCESS (NOTIONAL)

App Store 4:01 PM 65%

Don't Allow Health Access Allow

Health

"MyHeart" would like to access and update your Health data in the categories below.

Turn All Categories On

Allow or disallow "MyHeart" to access all health data types listed here.

ALLOW "MYHEART" TO WRITE DATA:

Height

Weight

App Explanation:
To fully contribute to MyHeart Counts it is important for our researchers to have access to the data contained in Apple's HealthKit. Please grant MyHeart Counts access to this data.

23 PATIENT HEALTH RECORD (NOTIONAL)

Care Plan

Go for a 15 minute jog or bike ride
Regular exercise decreases your risk of developing certain diseases, including type 2 diabetes or high blood pressure.

Health

Procedure	Cholesterol HDL
ACL repair	53.5 mg/dL
Triglycerides	**BMI-body mass index**
86 mg/dL	26 kg/m²

Allergies

Conditions

Sources | Health | Sharing | Account

24 SIGN IN: STEP 1

Sign In

Email

Password SHOW

Forgot password?

Sign In

In Security settings, offer the option for Touch ID & PIN.

Person shall receive appropriate security emails of an attempted sign in.

25 SIGN IN: STEP 2 (2FA)

Keep your account safe.

To make sure it's really you, we'll send you a code.

Mobile
(xxx) xxx-5555

If you select the phone number above, you confirm that you are authorized to use this phone number and agree to receive SMS texts to verify your identity. Carrier fees may apply.

Other options to confirm your identity

Send Code

26 SIGN IN: STEP 3 (2FA)

Confirm your identity.

Enter the code sent to your phone number ending in 5555.

Send code again

From Messages
451090

1 | 2 ABC | 3 DEF
4 GHI | 5 JKL | 6 MNO
7 PQRS | 8 TUV | 9 WXYZ
0

We may want to offer the ability for the PDM to remember/verify a device to simplify future sign in processes.

Remember this device?

In order to protect the security of your data, we'll ask you to verify your identity when you sign in from a new device. Remaining logged in for a long time or clicking "Remember Device" will make this process less frequent.

You can change this at any time in Settings.

Remember Device

Not Now

27 VIEWING LEGALESE BY TOPIC

YOU CAN SHARE YOUR DATA AUTOMATICALLY DURING AN EMERGENCY. FIRST RESPONDERS WOULD BE ABLE TO SEE CRITICAL HEALTH INFORMATION ABOUT YOU.

IN CASE OF EMERGENCY

Next →

28 SHOW LEGALESE (NOTIONAL)

Done

Emergency Access
In the case of an emergency during which Patient may not be able to authorize sharing of the LHD, Patient may grant permission to the PDM to share the LHD and delineate the parameters through which emergency sharing of the LHD may occur. Emergency access parameters and permissions may be established and updated at any time, and may be limited to specific information of particular importance during emergency treatment when Patient is otherwise incapacitated.

VII. Health Data Aggregation and LHD Updates

POM shall aggregate Patient's health data from each of the healthcare providers with whom Patient has executed SDRs into one cohesive, complete, longitudinal compilation of health data. Information can include but is not limited to medical records, medical imaging, medical image files such as X-rays or MRIs, lab results, and genomic sequencing data), billing records, and claims-related information.

POM shall enable the incorporation of Patient-generated health data (PGHD)

Highlight Color
#FEF8DF

MITRE PDM PATIENT DATA USE AGREEMENT STORYBOARD V05 (NOTIONAL)

ERIC BENOIT, PATRICIA NGUYEN, DANIEL REEVES, JUHAN SONIN – 23.MAY.2019 gov.mo