1

An open source project by MITRE. Email us.

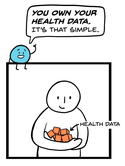
GET CONTROL OF YOUR HEALTH DATA

FOLLOW ME AND LEARN HOW

Let's Get Started

Sign In

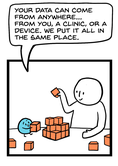
2



Next →

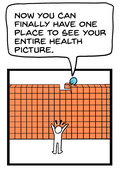
FEEDBACK: How do we want to represent progress?

3



Next →

4



Next →

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

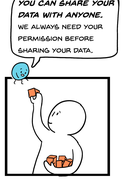
How is this a visual to "my health", "my soul"?

5

Next →

FEEDBACK: We need a disclaimer in the PDUA that indicates changing/deleting 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.

6



Next →

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

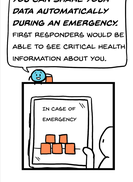
7

Next →

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

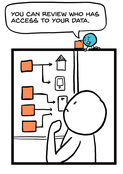
Prevent and treat illness is broader than cures, as most treatments aren't curative. I'm not sure if doesn't make the case as clearly though?

8



Next →

9



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?

10

Next →

FEEDBACK: Is this person a little too angry looking!

11

Next →

FEEDBACK: Who is they?

In screen 12, 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 "once" might be better.

12

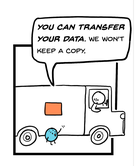
Next →

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, I was wondering if we might need to reiterate that for 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 would keep a record copy for a while without additional aggregation (for legal protection or near term customer reversal).

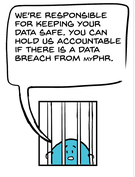
13



Next →

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

14



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?

15

Five steps left, continue →

16 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?

17 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.

18 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

19 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

20 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?

21 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.

22 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

23 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.

24 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

25 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.

26 VIEWING LEGALESE BY TOPIC

Next →

27 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 with emergency responders according which emergency sharing of the LHD may occur. Emergency sharing designations 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

PDM shall aggregate Patient's health data from each of the healthcare providers with whom Patient has executed DSAs into a single, comprehensive longitudinal compilation of health data. Information can include but is not limited to medical records (including diagnostic imaging files such as X-rays or MRIs, lab results, and genomic sequencing data), billing records, and claims-related information.

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

Highlight Color
#FEFBCF

MITRE PDM PATIENT DATA USE AGREEMENT STORYBOARD V05 (NOTIONAL)

ERIC BENOIT, PATRICIA NGUYEN, DANIEL REEVES, JUHAN SONIN – 18.JUNE.2019 gliinvo