

Self-Reported vs EHR Information Quality; Privacy for Individual and for Family Members

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No Difference in Family Health History as EHR FHH is Self-Reported

Your Personal Information

We start the family health history with you. Enter the required personal information and your health history information. At the bottom of the page (you may need to scroll), press the 'Next' button. You will then be asked to tell the system which family members you would like to add to the health history.

* Indicates required information.

*Name:

*Gender: Male Female

*Date of Birth:
mm/dd/yyyy

Were you born a twin? No Yes - Identical (Same) Yes - Not Identical (Fraternal)

Were you adopted? Yes

Height Feet Inches -OR- Centimeters

Weight lbs

Your Health Information

In the list below, select a **Disease or Condition** (if any) from the dropdown box. Then select the **Age at Diagnosis** and press the **Add** button. You may repeat this process as necessary.

Disease or Condition	Age at Diagnosis	Action
<input type="text" value="Please Select a Disease"/>	<input type="text" value="Select Age at Diagnosis"/>	<input type="button" value="Add"/>

Your Family Background Information

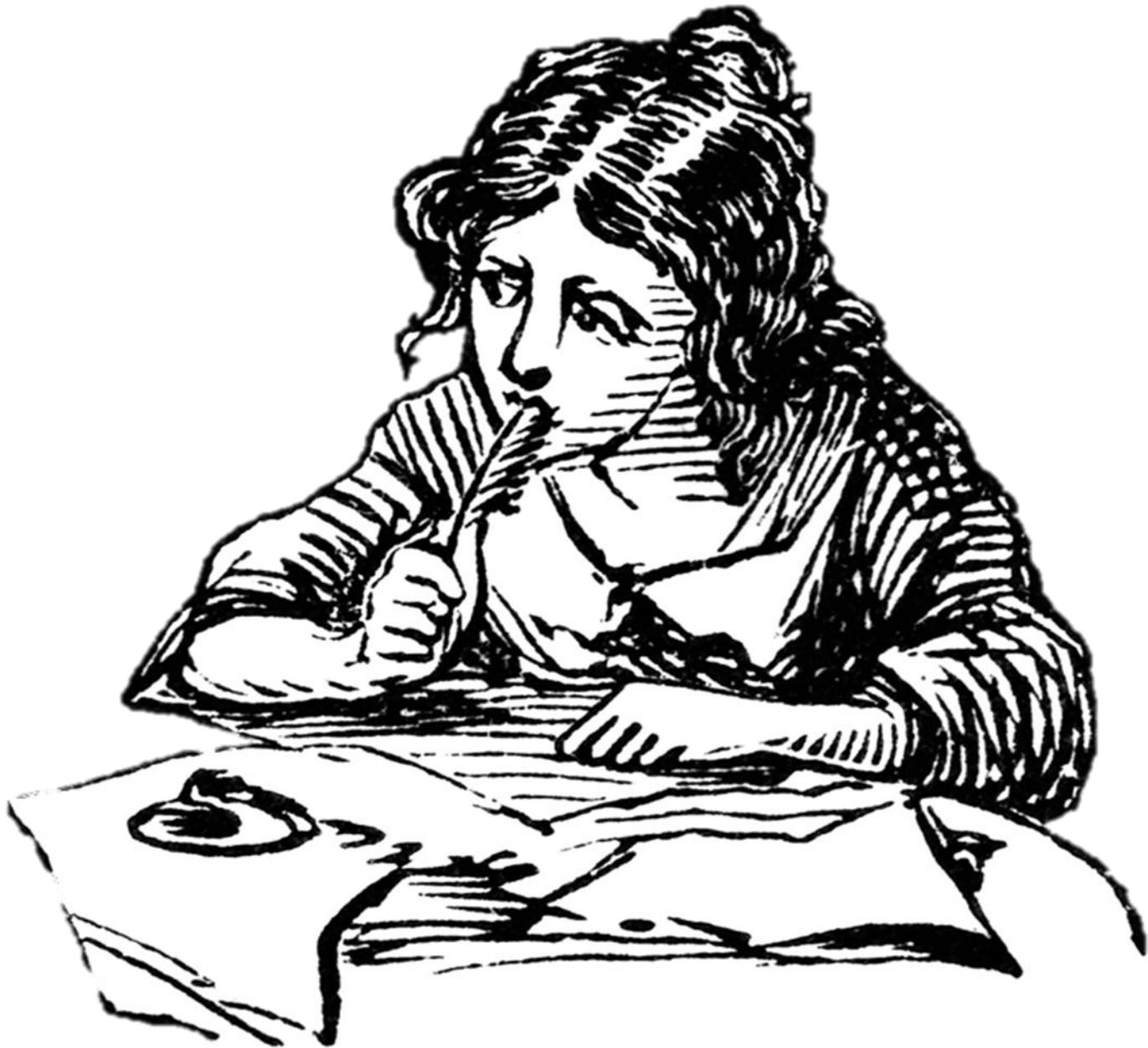
Check here if your parents are related to each other in any way other than marriage.

Multiple races and ethnicities may be selected.

Race: American Indian or Alaska Native Asian Black or African-American
 Native Hawaiian or Other Pacific Islander White

Ethnicity: Hispanic or Latino Ashkenazi Jewish Not Hispanic or Latino

[Why are we asking about Ashkenazi Jewish heritage?](#)





BANANA

BANDANA

BAND ANNA

We can't expect highly accurate family medical history if it is dependent on an individual's memory

“Garbage in, garbage out”



Your analysis is as good as your data.

Maximize quality of Family Health History

Have Family Members Each Put
in Their Own Information so
that it is Firsthand and
Accurate

... Share

**Include as Many Family
Members as Possible**

Adjust for Missing Family Members

How Does an Individual Collect Good Data?

Patient EHR Data

In EHRs, Physician Exam
and Labs are only Objective
data

Import Physician Exam Notes and Labs data

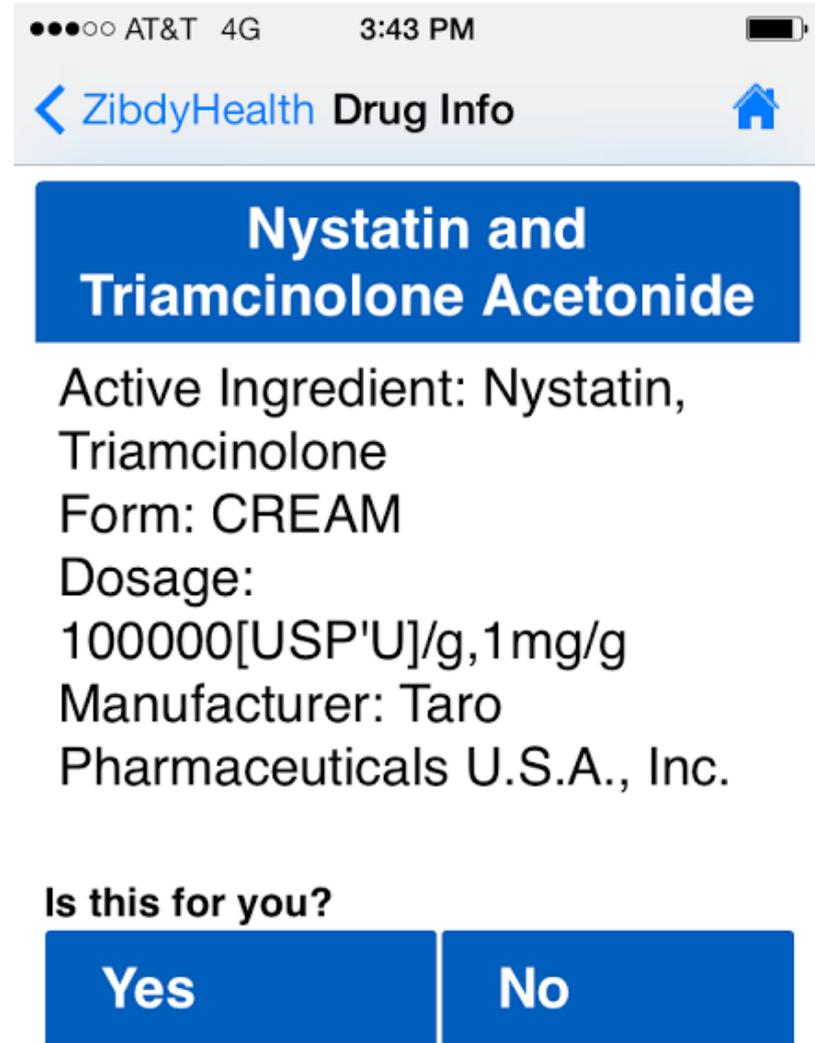
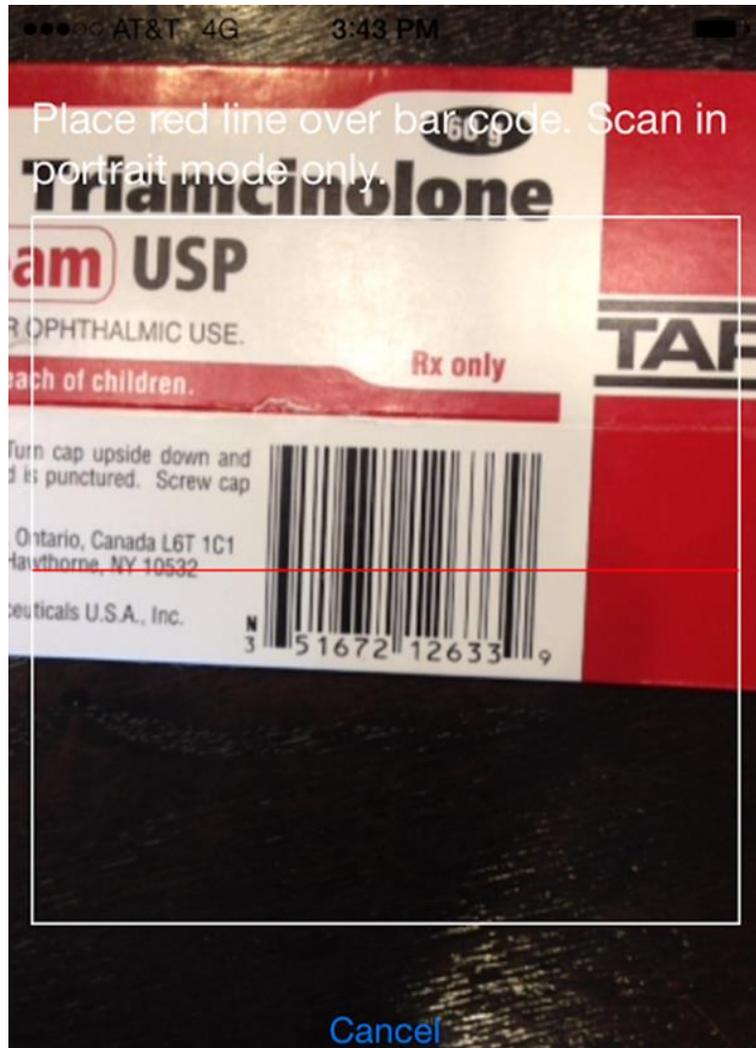
“Smart HIE” - Transfer Data Ownership and Makes Data Useful

User Entered Data

Unstructured to Structured Data

Scanning Medication List

Simple as 1-2-3



Fran Tribiani

Conditions / Illnesses

Family Medical History

Indications for 1st Degree

Relations

Medication

Breast Cancer	Cyclophosphamide
Diabetes Mellitus Type 2	Byetta
Sore Throat	Childrens TYLENOL
Back Pain	IBUPROFEN Children's (ibuprofen) suspension
Prostate Cancer	Taxotere
Cancer (high calcium levels in)	Dexameth
Others: Dry Eye	REFRESH TEARS
Skin Fungal Infection	Nystatin and Triamcinolone Acetonide

Indications for 2nd Degree

Relations

Medication

Breast Cancer	Gemzar
Breast Cancer	Cyclophosphamide



Breast Cancer (Fran Tribiani)

<i>Date Diagnosed</i>	<i>Date Cured</i>
10/9/2015	

Family members with this condition

<i>Family Member Name</i>
Rachel Wolowitz-Tribiani
Fran Wolowitz-Kramer

Will People Use an Application if
the Benefits are Many Years
Out?

Or Someone Else Benefits?

Use => Data => Share

Privacy and Sharing Data

Default Should be Set to
“NO” Sharing

Let Patient Control Sharing Preferences

Section and Item Level Privacy

Permissions and Privacy

iPad 9:33 PM 53%

[Select Permissions](#) Change Permissions 

Permissions allowed for Nurse Jaqui

	Add	View	Delete	Modify
Personal Info	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allergies	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medications	<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>
Medical History	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vaccines	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Labs	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reminders	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
Vitals	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		
Permissions		<input type="checkbox"/>		<input type="checkbox"/>
Notes	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		

Save

Patient controls permission through simple check-box

Conclusions

- Distributed data collection via “Family-sourcing” leads to collection and maintenance of **Accurate Family Health History**
- Giving patient control of their data allows them to determine access level to their data and making it easy for them to use your analytic tools for FHH



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