**Sample/Draft PLAIN LANGUAGE MODEL PATIENT DATA USE AGREEMENT**

**(Example Language for Data Aggregators Offering Services to Patients)**

I \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ [my first and last name] want to use the services of Company / Organization (Company) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ to collect and manage my personal health information. This requires me and Company to agree on each other’s rights and responsibilities related to the collection and management of my personal health information. In some cases, I can choose how I want to handle certain things like sharing my data. My agreements with Company and my decisions are documented here.

1. Collecting Health Information.

* Company will collect and display to me the personal health data it receives from my health care providers for my informational purposes only. I understand that Company is not providing medical diagnosis, treatment, or advice unless it specifically states that it does (for example, telemedicine).
* Company can only receive my personal health information if I tell my health care providers to send it to Company. Company can help me ask my providers to do this.
* My providers must send my health information to Company if I ask. I understand that I may have to follow different instructions from each provider so each provider may be sure that I want my information sent to Company. This protects my privacy.
* I can ask my providers if they have the technology to send my health information to Company as soon as it changes or is updated. [Include link to authorization/standing data release here]

2. Collecting Other Information.

* Company can collect and display other information, such as from a health tracker, my contact information, or my grocery receipts. This information can give me a better understanding of my health and wellness. I can choose what other information Company collects and displays here: [Add link].
* I understand that Company may need to collect at least one way to contact me and keep my account running, such as an email address, and may also need to collect my billing information if I am paying Company for the service. I understand that collection of information to do these things is necessary and may not be turned off.
* Company will explain all of the information it collects from me and why.

3. Ownership of All Information Collected by Company.

* The information collected by Company belongs to me.
* I can add notes to or ask questions about my information.
  + Adding notes to my held information in Company’s service does not add notes to my information anywhere else.
  + Company will keep track of my notes so a provider looking at information collected by Company will understand the difference between my notes and what came from a healthcare provider.
  + If I need to correct my health record at a health care provider, I must follow my provider’s process to make changes.
  + If Company is not the source of the health or other information but is only collecting it for me, Company may not have the answers to questions I ask about my information, and I understand that I may need to contact other people or companies for answers to my questions.
* I can delete my information or parts of my information at any time. Company may not keep a backup copy so I must be sure I want to delete the information. Deletions are permanent.
* I can download a copy of my information at any time.
* No one, including Company, can do anything with my information or see it without my permission.

4. Sharing Information

* I can share information Company collects for me with anyone I choose, and I can stop sharing with anybody at any time. If I tell Company to stop sharing information with someone, Company will stop sharing within 24 hours. To turn sharing on and off, I can go here: [Add link to this page/functionality here].
* Company cannot take back information I have shared.
* Company cannot promise that the people I share my data with will look at it.
* I can tell Company that I want some or all of my information shared in an emergency. I can choose what types of instances I believe are an emergency. I can update my emergency settings here: [Add link to emergency functionality here].
* Company will keep a record of who I have shared information with and who has viewed my information. This record is available to me here [Add link].
* Some services that collect patient data use pieces of patient information in research. This is often called deidentified, aggregated data. Company will ask me if I want to allow use of my information for these purposes. Company might offer to share with me some of the money it earns from using my information. There is a risk that my information could be compared to other information and I could be identified later. I can say yes or no to this type of use here: [If Company does this, insert line that says “To learn more about this, click here”].
* Company will not share my information without my permission. There may be times when Company will not have a choice, like if a court or law enforcement asks Company for my information. Company will notify me through the contact information on my account if this happens before Company provides the information.
* I can learn more about Company’s policies and practices related to data privacy and sharing here [Add link to privacy policy].

5. Protection of My Information

* Company will protect my information from being wrongfully seen or shared. I can review information on the different ways Company protects my data here [Add link to description of security here].
* Company will obey the strictest rules that protect health data, including the laws and rules in my state.
* To keep my information safe, I will not share my login information. If I want help managing my information with Company, Company allows me to name someone to help me. I can name this person here [Add link to page that provides patient with choice to name a proxy/agent]. Company will make sure that person has his or her own login information.

6. Protection of Company

* I, \_\_\_\_\_\_ [my first/last name], promise not to do anything to put Company at risk or to put Company’s customers at risk.
  + This means I will not try to break Company’s services or software, security and other protections, try to access other customers’ information, or behave in ways that are against the law or against this agreement. If I do, Company can end this agreement right away and, depending upon what happened, can file a report with law enforcement.
* I, \_\_\_\_\_\_ [my first/last name] promise not to steal Company’s trademarks, software designs or designs of the tools used to collect and display my data to me, or any other intellectual property belonging to Company.

7. If the Agreement is Not Followed

* If Company or I do not follow this agreement, Company or I can end the agreement. I can end the agreement here [Insert link to agreement termination page].
* I have the right to ask Company to make things right if Company has not followed this agreement. I can go to court if I think that is the best way to make things right.
* Company can ask me to make things right or go to court if I have not followed this agreement, or have acted or used Company’s services in ways that put Company or Company’s other customers at risk.
* If my information is used or disclosed without my permission, I can also go to state and federal agencies for help. For more information, click here [Add link to complaint/breach notification to Company plus links to HHS, FTC, and relevant state/local websites such as the state Attorney General].

8. Ending the Agreement

* I can end this agreement at any time by clicking here: [Account termination/cancellation request link].
* If the agreement ends due to my death, Company may provide me the ability in advance to opt to delete my information, transfer it to someone I name, or donate it to research. I can make or change my choice here: [Add link to page that enables disposition of data/access to account]. Company will also tell me how to let my friends and family know that they should notify Company of my death.
* **If I end the agreement**, Company will turn off information coming from my health care providers within 24 hours after I notify Company. I will have 30 days to download a copy of my data or transfer it to another application. After 30 days, Company will delete all of my data. Deletions are permanent and cannot be undone.
* **If Company ends the agreement**, it will tell me 60 days before the agreement ends and will ask me to confirm that I received the notice. If Company is ending the agreement because I broke the agreement, it may stop my access to Company’s services. If Company ends the agreement, no matter why it is ending the agreement, it will hold a copy of my information for my download for 60 days and then my information will be deleted; if the agreement has ended because I have not followed it or have acted or used Company’s services in ways that put Company or Company’s other customers at risk, Company may send me my downloaded information by email or the other contact information I have given it.

9. Notices and Updates

* I agree to keep my contact information current so that Company can share updates to this agreement or its services.
* Company will maintain a record of my choices related to this agreement and my electronically signed copy of this agreement here [Insert link to location of agreement]. If Company updates this agreement, Company will provide me with access to the updated agreement and describe what has changed. Company will also provide a notice on its website that an update to the agreement is available for review.
* I always have the option to change the choices I have made related to this agreement. I can review my current choices here [Insert link to location of agreement/list of selections].