

Appendix A

The consumer-led Patient Privacy Rights Trust Framework includes 15 clear principles:

- Principle # 1.** Patients can easily find, review, and understand the privacy policy.
- Principle # 2.** Privacy policy fully discloses how personal health information will and will not be used by the organization. Patients' information is never shared or sold without patients' explicit permission.
- Principle # 3.** Patients decide if they want to participate.
- Principle # 4.** Patients are clearly warned before any outside organization(s) that does not fully comply with the organization's privacy policy can access their information.
- Principle # 5.** Patients decide and actively indicate if they want to be profiled, tracked, or targeted.
- Principle # 6.** Patients decide how and if their sensitive information is shared.
- Principle # 7.** Patients are able to change any information that they input themselves.
- Principle # 8.** Patients decide who can access their information.
- Principle # 9.** Patients with disabilities are able to manage their information while maintaining privacy.
- Principle # 10.** Patients can easily find out who has accessed or used their information.
- Principle # 11.** Patients are notified promptly if their information is lost, stolen, or improperly accessed.
- Principle # 12.** Patients can easily report concerns and get answers.
- Principle # 13.** Patients can expect the organization to punish any employee or contractor that misuses patient information.
- Principle # 14.** Patients can expect their data to be secure.
- Principle # 15.** Patients can expect to receive a copy of all disclosures of their information.

The charts on the following pages illustrate the auditable criteria for each of the 15 principles that demonstrate whether or not an organization is in compliance with the PPR Trust Framework.

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
1	Patients can easily find, review and understand the privacy policy.	1.1	Privacy policy includes a short summary accurately describing the patients control of their data and all access to that data. The policy must specifically list any organizational personnel by organizational role that access data for operational purposes.			
		1.2	The policy must be easily accessible from the organization's home page.			
		1.3	Privacy policy must not use passive structures ("we share" vs. "the sharing"), qualifying verbs and adverbs ("use" and "will" vs. "may," "occasionally," and "from time to time"). We encourage the policy to use short sentences and small words.			
		1.4	Privacy policy must have topic headings that link to plain language explanations of the type of data accessed and how the data are handled. We encourage the use of charts and tables.			
		1.5	Privacy policy shall attain a Flesch Reading Ease score of 45 or higher.			
		1.6	Privacy policy shall attain a Flesch-Kincaid Grade level score of 12 or lower.			
		1.7	Privacy Policy shall use a minimum 9 pt. font.			
		1.8	Privacy policy is available in the native language of the organization's significant customer populations. Additionally, localization of deployment targets designated official language of jurisdictional area.			
		1.9	Privacy policy provides easy access to definitions of technical terms.			
		1.10	Privacy policy includes explicit language on process and notification of "material changes" and allows customers a defined timeline to opt out prior to policy changes.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
2	Privacy policy fully discloses how personal health information will and will not be used by the organization. Patients' information is never shared or sold without patients' explicit permission	2.1	Privacy policy states that personal information is collected only with informed consent, unless otherwise required by law.			
		2.2	Privacy policy must clearly state what the organization will and will not do with personal health information.			
		2.3	Privacy policy fully describes use of internet monitoring technologies, including but not limited to beacons, weblogs, and cookies.			
		2.4	Privacy policy fully describes all data sharing circumstances that require a patient to opt-in.			
		2.5	Privacy policy fully describes what ability the patient has to change, segment, delete, or amend their information.			
		2.6	Privacy policy fully describes who can access the information and when.			
		2.7	Privacy policy fully describes under what circumstances data are externally disclosed.			
		2.8	Privacy policy fully describes with whom data are shared.			
		2.9	Privacy policy fully describes how information is not disclosed.			
		2.10	Privacy policy describes how all access to data is recorded and how resultant audit trails are accessible to the patient.			
		2.11	Privacy policy describes procedures the organization will follow in the event of a security breach.			
		2.12	Privacy policy describes the organization's process for receiving and resolving complaints.			
		2.13	Privacy policy describes a mechanism for Third Party resolution of complaints.			
		2.14	Privacy policy confirms that all persons with access to the data must comply with privacy policies.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
3	Patients decide if they want to participate.	3.1	System provides clear notification of informed consent during registration. All patients must opt-in.			
		3.2	System allows patient to opt out at any time, and the opt out process must be simple and clearly stated in the privacy policy.			
		3.3	System provides capability for all access to the patient's data to be removed at any time. Patient has the ability to permanently delete all information upon closing an account.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
4	Patients are clearly warned before any outside organization(s) that does not fully comply with the organization's privacy policy can access their information.	4.1	Organization must contractually require all persons with access to data to clearly disclose whether they comply with its privacy policies. Audit trails are sufficient to verify data access compliance.			
		4.2	For internet applications, the organization must ensure patient can easily access any other website's privacy policy before linking to another site.			
		4.3	The organization shall prominently display the PPC™ seal of any organization that has obtained PPC™ certification prior to obtaining informed consent for information sharing.			
		4.4	Organization ensures visual indication distinguishing between outside organizations governed by HIPAA and outside organizations that are not governed by HIPAA with additional links to educational information explaining the difference.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
5	Patients decide and actively indicate if they want to be profiled, tracked, or targeted.	5.1	Any profiling must be optional (opt in) with the ability to opt out.			
		5.2	The system must allow patients to clearly identify data used for profiling and targeting.			
		5.3	Patients must be able to opt out of any profiling at any time. The opt out process must be simple and clearly stated in the privacy policy.			
		5.4	The patient may chose which specific data elements may be used for profiling and targeting.			
		5.5	Opting out of profiling and targeting has no secondary effects on the patient. This is clearly stated in the privacy policy.			
		5.6	The system never shares profiling data without patients' prior informed consent.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
6	Patients decide how and if their sensitive information is shared.	6.1	System allows patient to selectively release each element of their health information.			

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7	Patients are able to change any information that they input themselves.	7.1	System allows patient to delete, change, or annotate each element of their health information.			
		7.2	The patient may permanently delete their personal information from the system upon patient request.			

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8	Patients decide who can access their information.	8.1	Access to personal health information and system functions is limited by role-based and individual access.			
		8.2	System provides the functionality to control access to the data.			
		8.3	System provides functionality for access to specific system functions (e.g., viewing audit records).			
		8.4	The ability to control the type of access that is provided to the system (e.g., read, write, delete) is controlled by the patient.			
		8.5	The system specifies how long access to data is available (e.g., indefinitely or one week).			
		8.6	Organization must document processes in place for emergency access to data and demonstrate that the procedures are operating effectively either through testing or analysis of actual events.			
		8.7	All aggregation processes must be documented and assure that the organization uses state of the art methods to prevent the disclosure of identifiable information.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
9	Patients with disabilities are able to manage their information while maintaining privacy.	9.1	Corporate commitment to Section 508 of the Rehabilitation Act in 1998 and specific Voluntary Product Accessibility Template (VPAT) for product.			
		9.2	Full compliance to 508 and VPAT.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
10	Patients can easily find out who has accessed or used their information.	10.1	Organization maintains audit trails of every event. Retention cycles for maintaining audit trails are based on the minimum HIPAA-entity requirements (e.g., six years).			
		10.2	Audit trail includes who performed the action.			
		10.3	Audit trail includes what action was performed.			
		10.4	Audit trail includes what data object was involved.			
		10.5	Audit trail includes when the action occurred.			
		10.6	The system does not allow the audit trail function to be "turned off." The audit record cannot be altered, and records do not expire.			
		10.7	Audit trails must be readily available to the patient.			
		10.8	Audit logs can be searched or filtered by who performed the action.			
		10.9	Audit logs can be searched or filtered by what action was performed.			
		10.10	Audit logs can be searched or filtered by what data object was involved.			
		10.11	Audit logs can be searched or filtered by when the action occurred.			

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11	Patients are notified promptly if their information is lost, stolen, or improperly accessed.	11.1	Organizations must, following discovery of a breach of personal health information, notify each individual whose information has been, or is reasonably believed to have been, accessed as a result of such breach. Organization must comply with the most restrictive federal or state requirements, which, at this time, is the breach notification law of the State of California			

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12	Patients can easily report concerns and get answers.	12.1	The organization must have a process that enables patients, advocates, employees, and government regulators to report potential or actual privacy violations.			
		12.2	The organization must acknowledge a patient's concerns, investigate, and inform the patient of the outcome of the investigation and take any corrective action within fifteen business days.			
		12.3	The organization provides a link to the PPC™ website allowing the patient to file a complaint with PPC™ if the matter is not resolved by the organization to the patient's satisfaction.			
		12.4	The organization will provide a quarterly report to PPC™ that describes the privacy complaint, resolution, and actions to ensure the problem does not recur.			

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13	Patients can expect the organization to punish any employee or contractor that misuses patient information.	13.1	The misuse or improper access of confidential personal health information must include penalties up to and including termination of employment and referral to public prosecutors.			
		13.2	All key personnel with system access must have at least one data of privacy training on an annual basis. On an annual basis, all personnel with system access must have at least: <ul style="list-style-type: none"> • One hour of privacy training • One hour of security training 			
		13.3	All personnel with system access must sign appropriate annual agreements to illustrate their understanding of the organization's privacy policies.			

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14	Patients can expect their data to be secure.	14.1	The system has undergone a security assessment by an independent third party, and there is a viable plan in place to mitigate any identified issues. (Reference PPC website for a list of Third-Party assessors and certifications accepted by PPC.)			
		14.2	The organization has designated a person with responsibility for and authority over privacy matters.			
		14.3	Organization only stores patients' information in the United States, its territories, or in countries that meet the requirements of the EU Data Protection Directive.			
		14.4	Organizations have processes and tools in place to identify and track where patients' information is allowed to be stored by the organization or its business partners acting on its behalf.			

#	Principle	Req. #	Requirement	Status	Document XREF	Comment
15	Patients can expect to receive a copy of all disclosures of their information.	15.1				