

Tool: Compare Features of Data Collection Methods

This tool helps you select the data collection method that meets your registry goals.

	<i>[Name of option 1]</i>	<i>[Name of option 2]</i>	<i>[Name of option 3]</i>	<i>[Name of option 4]</i>
Cost				
What is the cost of using the data collection method?				
Is there a set-up fee??				
Is there a monthly/annual fee?				
What features does the fee include?				
Notes				
Information Technology (IT) Knowledge				
How much computer knowledge is needed?				
Is there technical support for users?				
Notes				

Form/Survey Features				
Is there a limit to the number of questions?				
Is there a question library? Are there questions specific to rare diseases?				
Can you customize your questions?				
Can you ask conditional questions? (i.e., uses answers for relevant previous questions on form/survey)				
Can you customize the form/survey (e.g., colors)?				
Can some fields be required?				
Is there a limit to the number responses?				
Notes				
Accessibility/Participant Experience				
Is the tool mobile-friendly?				
Does it explain how to fill out the form?				
Does it provide help for understanding what a question means?				
Is it easy to share a link?				
Are different languages available?				
Is the form easy to read and complete?				
Can patients save incomplete forms and return later to finish?				
Do patients have the capability to edit/modify their answers?				

Notes				
Data Usability				
Is the data easily accessed, managed, and used?				
Does the tool have the capability to display data visually or graphically?				
Notes				
Data Usability (continued)				
Can data be collected and displayed in real time (e.g., via a dashboard)?				
Can you receive notifications when a form is completed?				
Can the data be exported into forms, sheets, or other programs or applications for sharing?				
Notes				
Sustainability				
How stable is the tool or service?				
What happens if the tool or service ends?				
Who owns the data?				
Are measures in place to protect the patients' data and privacy?				
Notes				

