Purpose: To design a patient portal from the perspective of patients and family caregivers, to be used in collaboration with healthcare partners in hopes of improving portals for all.

Patient portals are, typically, built without including patient and family caregiver perspectives. To meet the National HIT PFAC’s vision of improving patient portals, we gathered the patient and family perspective through an informal survey. The survey responses created the concept for a perfect patient portal. This opportunity was open to all patients with experience using patient portals, and not specific to one portal or another.

A total of 60 responses were collected through the National HIT PFAC’s community connections and the PFAnetwork. We asked that PFAnetwork members share the request with their patient communities. We asked for three most desirable features, three least desirable features, and a description of their perfect portal without restrictions and unlimited resources. The breakdown of responses by vendor was:

- 41 Epic
- 13 Cerner
- 1 Homegrown
- 21 Unknown

“My perfect patient portal would be centered on me.”

Based on the responses, the perfect patient portal would:

- Support the patient-physician relationship
- Be accessible from anywhere
- Have an easy log in process
- Be completely customizable
- Capture patient’s goals and preferences to inform physicians
- Have access to physician notes
- Give a current snapshot of overall health
- Provide health education and technology support

Most Desirable Portal Features

- Communication with physician
- Receiving test and lab results
- Scheduling appointments

Least Desirable Portal Features

- Lack of communication
- Confusing technology
- Lack of interoperability

“I live 75 miles away from these providers so the ability to ask questions and send pictures makes me feel very secure. Also, questions are answered and followed up on in a timely way.”

“[I can send an] email to provider for needs that do not need an appointment.”

“Patients should have a way to comment on and clarify their own records.”