

Priority Research Questions—Young Adult Patients in San Francisco

1. What can doctors and patients do to speed up the process of getting to a diagnosis or treatment (e.g. authorizations, waiting for results one at a time)? What can be done to better coordinate tests and consults?
2. What can be done if my medications stop working? Especially if there is not a new one available?
3. What are the long-term effects of medications, and stopping/starting medications? Does age affect side effects? How can side effects be prevented?
4. How do you find doctors/specialists who are willing to work with more complex/complicated patients and are willing to coordinate with other doctors?
5. How do you help young people “grow up.” How do I know who is worth investing friendship, emotional energy in? How can patients learn to talk about their condition to others, how to make that process easier, find their voice, be more comfortable?
6. How do you determine what your new normal is and where to put your energy, in terms of what symptoms can be improved?
7. How can patients cope better with uncertainty and worries about the future?
8. What can be done to make medications more affordable? What can be done to make cost information more transparent or accessible? How can healthcare providers help patients plan for paying for future treatment? Understand pros/cons risks of jobs and cost of care?
9. What can be done to promote hope? Keep aspiration for the future? And be a person outside the disease?