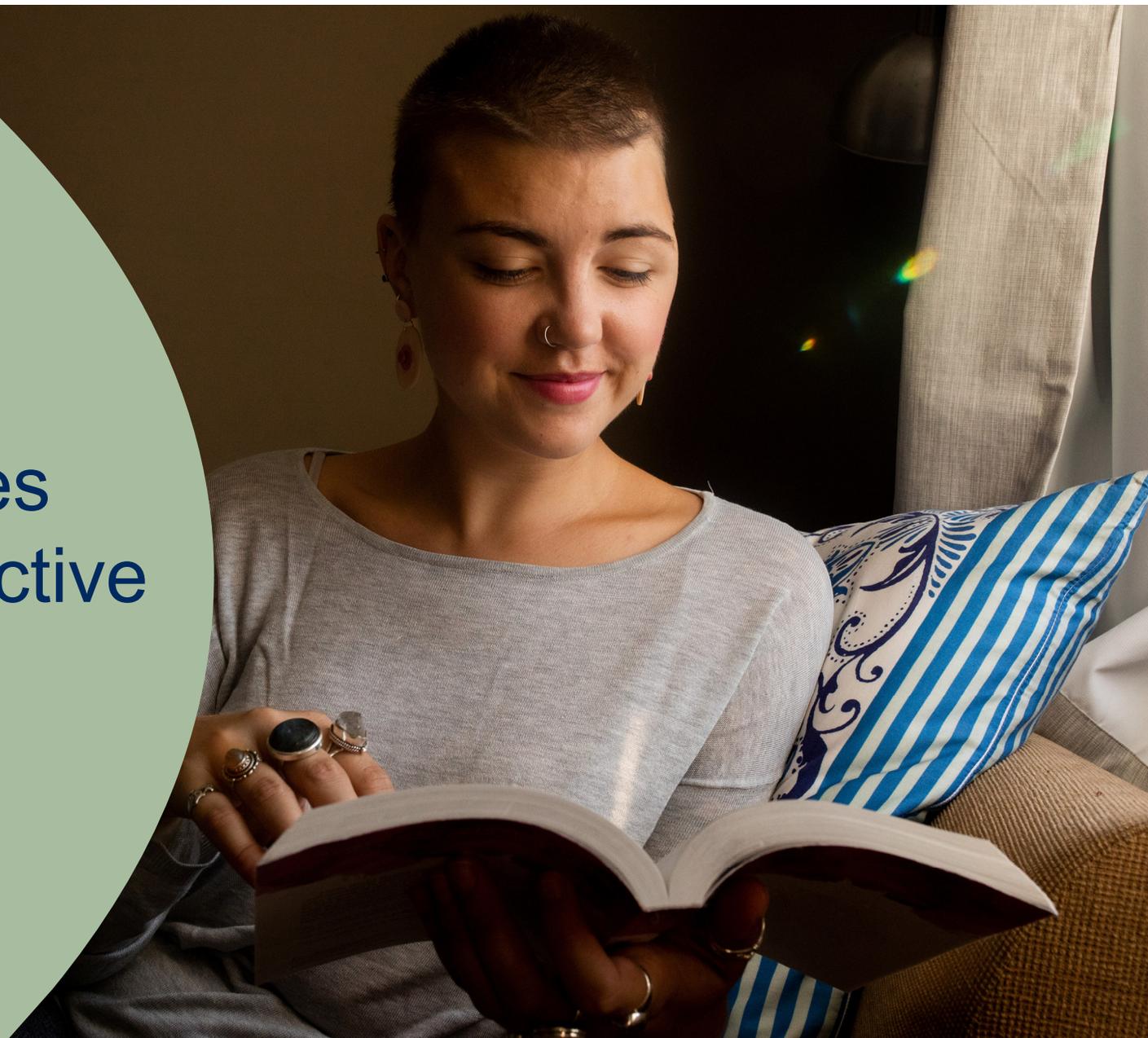


SAKK Lay Summaries A Patient Perspective

Zurich
20 Nov 2021



Who is this patient?

What's her experience?

Double cancer diagnosis in Oct 2019. Today in complete remission, including mentally, I forget I have been ill

- A single (recently widowed) mother of **2 young men** (19 & 21) and **unemployed** – these are my real concerns.
- I have had an excellent **experience** in Zurich health care system, despite the complexity of my condition
- Treated at **3 or 4 different departments/sections** in the USZ hospital
 - effective coordination across all 3
 - cross-effects of treatments seem to be considered thoroughly
 - good pace of treatment, can never be fast enough of course
 - deep differences of care/expertise/communication across departments
 - weekends in hospital, like a different hospital
- Super **steep learning curve from zero** about these diseases, options available, terms used, side effects, probabilities, statistics, side effects (i.e., from several full anesthesia), radioactive substances used, etc.

What were difficult parts?

I often struggled to find and understand the literature to inform me about my decisions or the doctor's recommendations

- Where to find information? It is hard to find relevant information
- When found, it is hard to know if source reliable
- If reliable, is it applicable to me? Or if not fully, which parts are applicable?
- And what does it mean? What is the "so what" for me?
- Are these the latest findings or are there newer findings/recommendations? How to know that is outdated, what is better?
- Many specific medical terms are hard to understand and to find definitions that apply

What information would be helpful to a trial participant?

What format?

Similarly, if I was a participant on a clinical trial, I would want to understand the trials' Context, Actions and Results (CAR)

- The location of information, where to find it, under what name, what reference, what website
- The organization leading the trial, the dates and milestones (plus or minus) incl. years of experience at this
- The various combinations of therapies/medicines being tested
- The population that is included in the trial, and if possible, the rationale
- The outcomes, with a commentary vs. expectations
- The “so what” or conclusions in a digested format, i.e., “so this means that option M is...” and a comparison vs. the next best standard

Format – ideally three summary formats would be available, all in lay terminology

1. a one-page text with an abstract of the test design and the outcomes
2. a max five-page summary with more detail vs. 1 pager above
3. an infographic or a summary with visuals/charts/icons, painting a picture of the trial design and its results – for the visually minded among us

Questions?