## **PATIENT** INCLUSION COUNCIL

## PATIENT/CAREGIVER SURVEY - FOR EXISTING DRUG REVIEWS/DRUG REPORTING

- ENDPOINT #1: Diagnosis and Subgroups
  - Diagnosis (is this a diagnosis for which drug is indicated for use)
  - Disease impact on daily life
  - Other Diagnoses (comorbidities/multi-morbidities, these matter for drug choice)
  - Patient Subgroups (precision medicine/not population level decision-making)
- ENDPOINT #2: Drug Usage
  - Start date (determine usage duration, if still on drug, or how long ago they used it if not currently on - as reporting a drug past a few years after stopping use is less credible data for use in a drug affordability review today)
  - Reason for choosing this drug (doctor, insurance required, difficult to treat, etc.)
  - Current use/past use
  - Reason for discontinuation, if applicable
  - Other drugs you've tried (PDABs will consider this for Alternative Therapies, we need to show trial-and-error process/precision medicine)
- ENDPOINT #3: Out of pocket costs for the patient associated with this drug and <u>only</u> this drug
  - OOP monthly costs *by time of the year*
- ENDPOINT #4: What is affordable <u>to the patient</u>?
  - Context is this drug alone unaffordable or is it a broader issue? (Obtain the 'why')
    - ENDPOINT #4b: Adherence (due to cost or other contextual factors) Identify cause of stretching or skipping a dose (i.e., due to the cost of this drug and this drug alone, cost of all healthcare bills a month combined, due to insurance protocols, simply forgot, etc.)
- ENDPOINT #5: Impact of the drug for treating this disease
  - Benefits
  - Negative health effects
  - Other drugs used (alternative therapies)
- ENDPOINT #6: Other costs
  - Other financial impacts or costs (not including this drug)
  - Other situations related to disease management impacting time spent
  - Other prescriptions (for any condition) and total OOP costs per month associated with them
  - Comparison between cost perceptions/affordability perspectives
    - OOP cost of this drug only
    - OOP cost of all drugs patient takes
    - OOP cost of drugs for household
- ENDPOINT #7: How does a person's healthcare plan impact OOP cost for this drug?
  - Health insurance at the time of taking the drug
  - Additional situations with health insurance that could impact cost or access
- ENDPOINT #8: Effectiveness of payment assistance programs to help offset costs