

PATHWAY TO POSITIVE PATIENT ENGAGEMENT

Patient As Partners = Outcomes that Matter

Effective engagement embraces patients, families, and caregivers as co-developers of decisions that impact their health. Consultations on health policy and research must also include equity-seeking groups, and marginalized communities as well as utilize real-world evidence and lived experience as data for decision-making.

1 PREPARATION



- Ensure the highest-impact decisions have the highest level of engagement
- Resource the plan, assign staff and budget including patient reimbursement
- Use plain language terms of reference, forms and documents

2 RECRUITMENT

- Develop a diverse and inclusive recruitment plan
- Include participation from affected communities
- Ensure a balanced representation of patients and caregivers while practicing cultural safety and a trauma-informed approach



3

ORIENTATION



- Review documents and provide opportunities for questions and feedback
- Explain compensation and reimbursement
- Discuss accommodation and support needs like dietary, respite care and transportation

5

FOLLOW UP



- Immediate – thank participants and identify next steps
- Close the loop – review how their contributions were used
- Evaluate results and impact, address concerns

4 MEETINGS



- Distribute materials well ahead of time
- Provide a detailed agenda with complete logistics
- Identify how the input will be used
- Ensure all participants have equal opportunity to contribute
- Use lay language, avoid jargon and acronyms

Foundations:

- Equitable
- Patients are experts
- Respect, empathy, trust
- Ethical and confidential
- Accountable