

Patient & Family Engagement (PE) in Research: A Tip Sheet for Graduate Students



DO'S

DON'TS

- Connect with PE leaders for information:
 - CIHR - SPOR
 - Child-Bright network
 - Canchild
 - Holland Bloorview Research Institute
- Find partners via your mentors, institution, organizations, databases, & social media

Learning the ropes & finding partners

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- Don't ignore the literature on PE
 - Don't wait until you're halfway through a study to invite partners
- Don't stop at 1 patient partner - seek diverse experiences & perspectives



- Be open, approachable & trustworthy (e.g., "get to know you" meetings)
- Discuss communication preferences (e.g., times, methods)
- Recognize & discuss potential barriers (e.g., access to literature, onboarding)
- Publicly acknowledge the partnership (e.g., show thanks, invite to co-present or co-author publications)

Building Relationships

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- Don't assume relationships grow overnight - keep nurturing the relationship throughout the study & beyond
- Don't disappear! Sometimes research takes a backseat, but relationships shouldn't. Keep your team updated
 - Don't avoid "harder" topics (e.g., finances) - instead be open & honest



- Establish & regularly review terms of reference for each team member (e.g., goals, values, expectations)
- Discuss the level of involvement (collaborator, equal partner) & stage of involvement of each partner (e.g., planning, recruitment)
- Co-create a clear PE plan.

Determining Roles

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- Don't dictate roles - collaborate to build on everyone's strengths
 - Don't rely on one partner. Avoid tokenism
 - Don't expect more than what is agreed upon or overburden partners



- Seek input on gaps & research directions
- Be clear about academic constraints (e.g., dissertation requirements)
- Consider including a partner on your dissertation committee

Prioritizing Questions

- Don't wait! Co-creating a plan early will foster meaning & passion
 - Don't neglect patient-indicated priorities. Find an appropriate balance between partner priorities and committee expectations



- Plan ahead - it can take time to establish relationships, & some aspects of the research process may take longer (e.g., onboarding)
- Respect your partners' level of time & involvement (e.g., to review documents)

Time Management

- Never underestimate time. Respect everyone's timelines, if anything
 - overestimate
 - Don't assume people are okay with changes. Have open conversations about adjusting times & commitments



- Seek funds to cover partner expenses and their time. Refer to guidance on rates (e.g., INVOLVE, PCORI, & CIHR)
- Have open conversations about finances early...Review policies, discuss methods of compensation (e.g., money, gift cards, travel expenses), & implications (e.g., taxes, disability) & avoid upfront expense

Expenses & Compensation

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- Don't assume partner preferences for compensation (e.g., if they want it, when, how much, type)
 - Don't delay reimbursement for partners' out of pocket expenses (e.g., parking or travel). Be prompt.
 - If unable to secure funding, be honest & continue to look for opportunities



- Seek out training for everyone around tips, collaborations, glossaries (e.g., CEPPP, HIPxChange, SPOR, IPFCC, The Patient Experience Library)
- Evaluate as you go - use tools to understand what worked, what didn't, & what could be improved (e.g. CEPPP)

Education

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- Don't underestimate the barriers grad students face - continue to seek training
 - Don't be afraid to incorporate PE - do readings & look at resources, tools, & organizations to get more information



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