

PATIENT-RESEARCHER ENGAGEMENT IN HEALTH RESEARCH

COMPETENCIES, STRENGTHS,
READINESS TOOLS, & SUGGESTED COURSE CONTENT

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The Strategy for Patient-Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit is a network of services designed to increase the quality and quantity of patient-oriented research conducted in the province. The Alberta SPOR SUPPORT Unit is jointly funded by Alberta Innovates Health Solutions (AIHS) and the Canadian Institutes of Health Research (CIHR) and draws expertise from its partner organizations: CIHR, AIHS, Alberta Health, Alberta Health Services, University of Alberta, University of Calgary, University of Lethbridge, Athabasca University. Further information about the Alberta SPOR SUPPORT Unit can be found here:

www.aihealthsolutions.ca/initiatives-partnerships/spor/

The views and opinions expressed in this report are those of the authors and do not necessarily reflect those of Alberta SPOR SUPPORT Unit's funding, or partnering organizations.

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Table of Contents

Introduction

Background

Definitions

1. Outline of Competencies for *Patient* Engagement
2. Strengths and Readiness Assessment Tool
3. Outline for Education and Training in *Patient* Engagement in Research
4. List of Currently Available Education and Training

References Cited

Appendix – Resources

Figures, Tables, Tools

Figure 1. AbSUPPORT Unit Spectrum of Patient Engagement in Research (adapted IAP2 Spectrum)

Figure 2. AbSUPPORT Unit Patient Engagement Platform Engagement Spectrum for Researchers

Figure 3. AbSUPPORT Unit Patient Engagement Platform Engagement Spectrum for *Patients*

Figure 4. AbSUPPORT Unit *Patient* Engagement Platform Flow Chart

Figure 5. Knowledge Areas and Skills for Researchers and *Patients*

Table 1. Competency for Inform Level of Engagement

Table 2. Competency for Consult Level of Engagement

Table 3. Competency for Involve Level of Engagement

Table 4. Competency for Collaborate/Partner Level of Engagement

Table 5. Competency for Empower/Lead Level of Engagement

Table 6. Recommended Outline of Education for Patient and Researchers

Table 7. List of Currently Available Education and Training

Tool 1: Strengths, Engagement, and Readiness Assessment Tool

Tool 2: Strengths, Engagement, and Readiness Assessment Tool Key

Tool 3: Sample Scoring of Assessment Tool

Introduction

CIHR has developed a curriculum and a discussion paper related to competencies for *patient* engagement in health research, but these items have yet to be approved or recommended for use by SPOR Support Units. Without any Pan-Canadian resources available to the Alberta PE Platform and the growing demand for support from researchers, the Alberta PE Platform made the decision to begin its exploration and development of the competencies and the recommended content for education and training for *patient* - researcher engagement in health research. The overall goal of this report is to provide:

- 1) An outline of competencies recommended for patient-researcher engagement in health research.
- 2) Tools to assist in determining the level of engagement that may be of interest to both patients and researchers and their readiness to engage.
- 3) A recommendation for course content appropriate to the identified level of engagement.
- 4) A list or environmental scan of available educational content, courses, and training that would be applicable.

This report has been developed in reference to an adaptation (Vandall-Walker, 2015) of the International Association of Public Participation (IAP2) (2014) [4] spectrum of engagement. All sections of this report are interconnected and build upon each other but are presented separately. This report will require continual review and discussion with key audiences (*patients*, researchers, SPOR Support Units, networks, institutions, and funders) for validation:

- 1) Approach
- 2) Content
- 3) Feasibility
- 4) Practicality
- 5) Impact

In addition to the four sections, a flow chart was created to support the PE Platform in their operational processes (see Figure 4).

Background

The *Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework* [1] identified capacity building as a key activity for SPOR SUPPORT Units, SPOR Networks, and jurisdictions. There are two questions in the report worth reiterating because they should drive planning and guide strategic development.

1. What actions can support researchers, health care providers, and decision-makers in engaging patients and to see the benefits of patient engagement (PE)?
2. What needs to be in place so that patients are willing to participate in producing and using health research? (Canadian Institutes of Health Research, 2014)

An area of concern that has been identified and documented is the lack of coordinated, consistent, and available education and training to prepare and support engagement for all stakeholders within the Canadian research context. Development of education and training for researchers and *patients* to engage and work together to produce research begins with the individuals involved. What are the skills, behaviours, and attitudes that need to be in place or be learned? A curriculum [2, 3] that addresses underdevelopment and core competencies [2, 3] is being drafted by the Canadian Institute for Health Research (CIHR); however, the *Patient Engagement (PE) Platform* needs to implement tangible, applicable tools and materials now, to promote, foster, and drive patient-researcher engagement in Alberta.

Key Definitions

Patient: An overarching term inclusive of

- Individuals with personal experience of a health issue
- Informal caregivers, including family and friends

Note: This term is always italicized when used in this document in relation to the AbSPORU PE Platform, to call attention to this broader meaning.

Patient Engagement in Research (PER): Meaningful and active collaboration in:

- Governance (including ethics and funding review, and as members on Research Advisory Committees and Working Groups)
- Research, across the process in any or all phases, i.e., preparation/planning, design/execution, and translation/dissemination (can include priority setting).
- While individuals who are recruited as participants or subjects are engaging with researchers, this traditional role for patients is not the focus of the SPOR initiative, or of the Patient Engagement Platform in particular.

Patient-Oriented Research (POR): A continuum of research that:

- Engages *patients* as PARTNERS
- Focuses on *patient*-identified topics
- Improves patient outcomes

Meaningful Patient Engagement: Refers to ACTIVE *patient*-researcher engagement as partners (Shippee et al., 2013):

- At any or all phases of the research process: preparatory/planning, design/execution, and translation/dissemination.
- Can include active participation in governance (proposal and ethics review, and as members of Advisory Committees).
- Is informed by Canadian Institutes of Health Research (2013) strategy for patient-oriented research (SPOR) guiding principles of inclusiveness, support, mutual respect, and co-building.
- Other foundational principles relate to trust, transparency, honesty, and valuing reciprocal relationships, co-learning, and partnerships (Patient-Centered Outcomes Research Institute, 2014).
- “Legitimacy, credibility, and power” of *patients* (Boivin, Lehoux, Burgers, & Grol, 2014) need to be considered when patients and researchers choose to engage.

Tables of Competencies for *Patient-Researcher Engagement*

Section 1 consists of competencies to be achieved for *patient* engagement in research. These competencies are the skills, knowledge, and attitudes/behaviours that lead to successful engagement. Competencies help guide the learning and knowledge to be acquired, shared, and understood, to support the activities and goals of establishing, building, and enhancing collaborative partnerships between *patients* and researchers. A basic search of competency frameworks from the fields of health, medicine, public/citizen/community engagement, and research helped in the development of this outline.

The CanMEDS 2015 Physician Competency Framework [5] and the Canadian Interprofessional Health Collaborative (2010) Competency Framework [6] was used as the foundation to construct the competencies recommended for *patients* and researchers to support capacity building as identified in the *Strategy for Patient-Oriented Research: Patient Engagement Framework and Strategy for Patient-Oriented Research: Capacity Building Framework* (CIHC, 2015) [7].

An inventory of competencies is listed in the following illustration and corresponds to the International Association of Public Participation (IAP2) spectrum [4] that has been adapted (Vandall-Walker 2016) to focus on engagement in health research.

For each level of engagement, competencies are listed, but the intention and application is that the competencies are progressive as the levels of engagement increase. As well, it is not expected that every single competency will be mastered for each level of engagement; however, basic proficiency should be met to build capacity and capabilities in *patient* -researcher engagement. It is recommended that if there is a choice or decision to be made to engage at the upper range of the spectrum, that basic proficiency from previous levels will have been attained. This can be assessed in part, by asking individuals to complete the *Strengths and Readiness Assessment tool*.

The IAP2 spectrum and goal statements have been adapted to specifically address the need, context, and vision identified by the AbSPOR SUPPORT Unit PE Platform (Figure 2). The goal statement for each level of engagement requires feedback and discussion before finalizing Figures 2 and related Figures 3 (adaptation in relation to researchers) and 4 (adaptation in relation to *patients*). For the purpose of defining competencies at each level of engagement, these statements are a useful frame of reference.

Figure 1. AB SUPPORT Unit PE Platform Patient-Researcher Engagement in Research Spectrum - Adapted from the IAP2 Spectrum (2014)

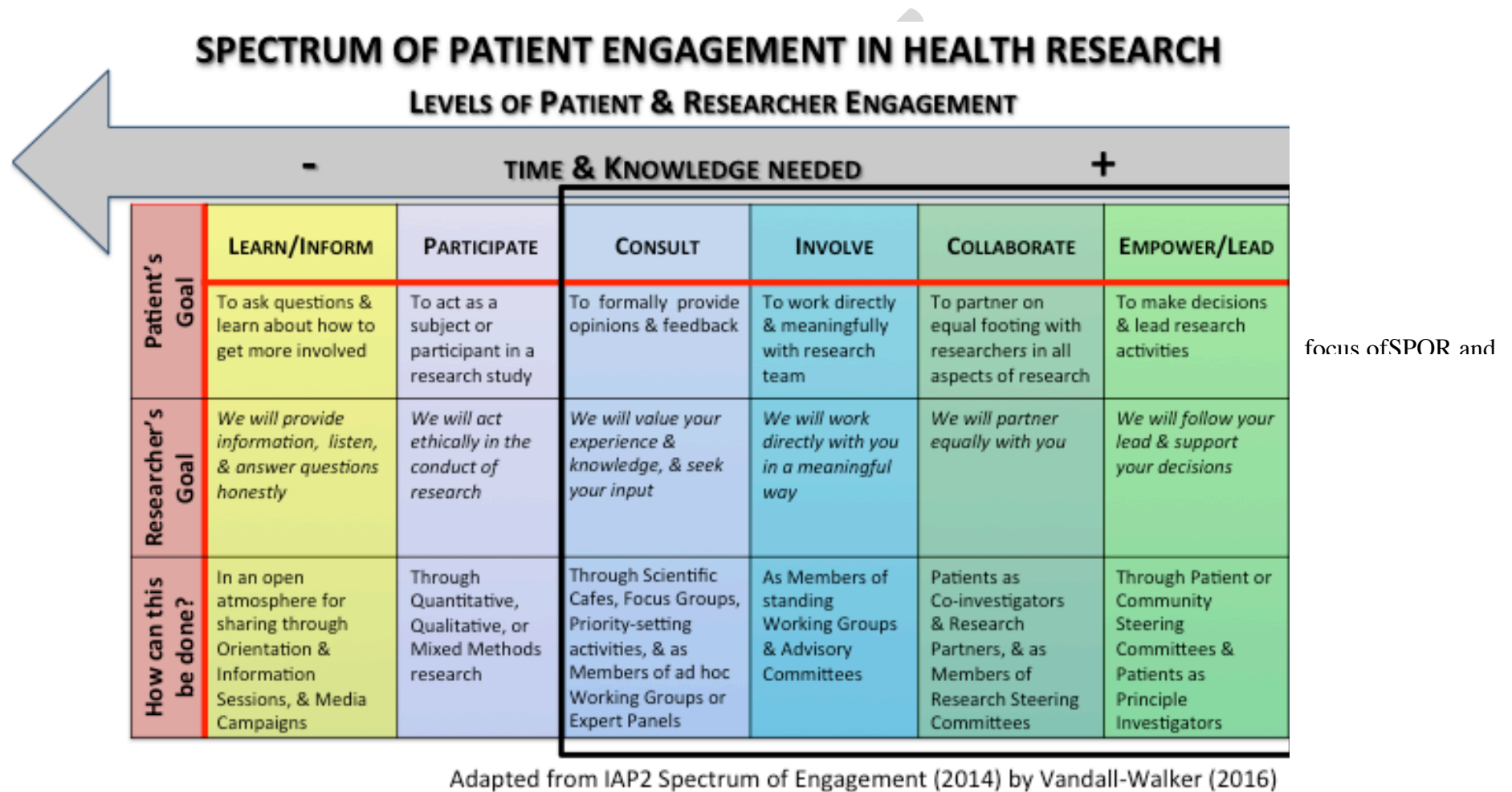
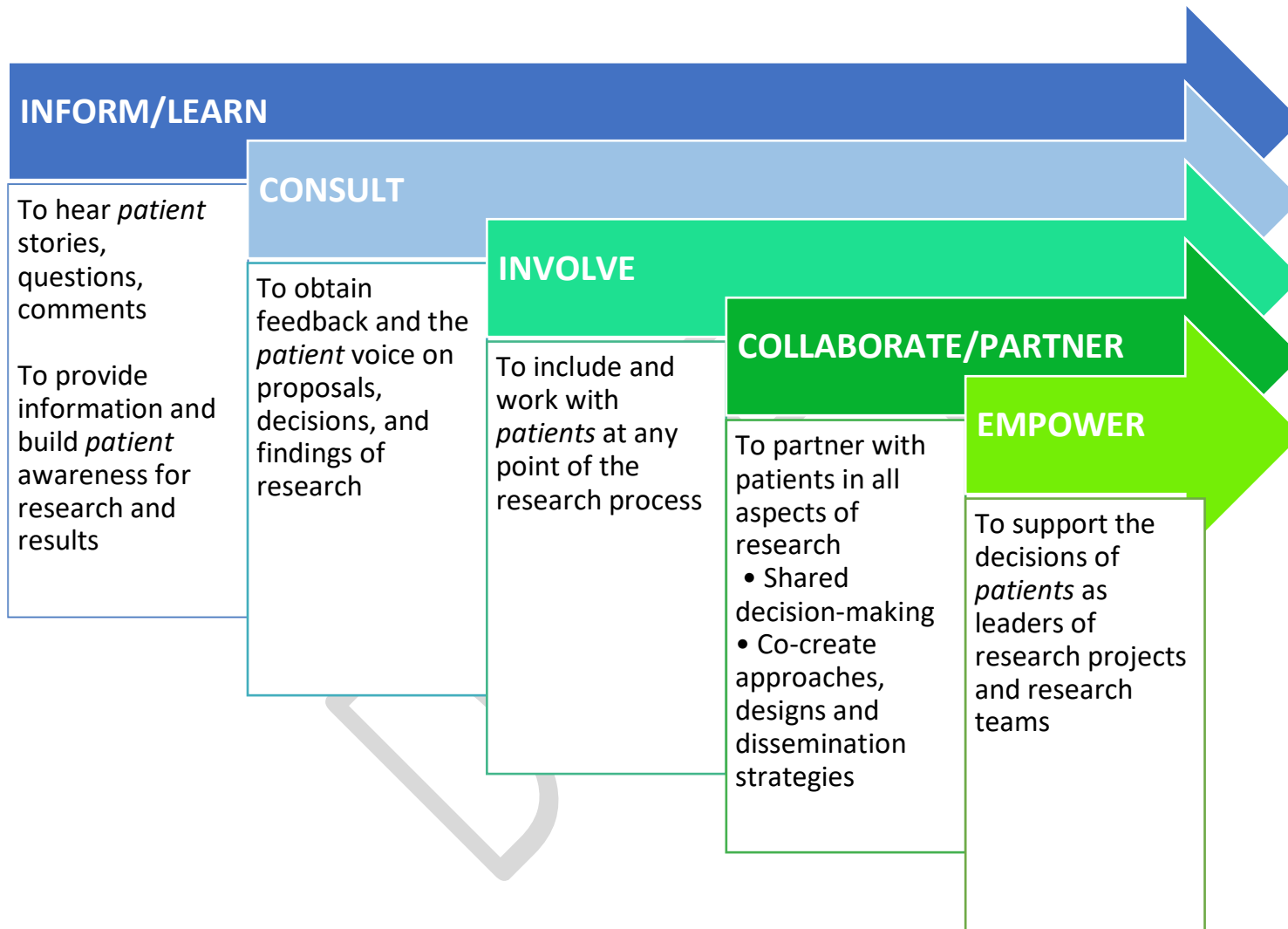
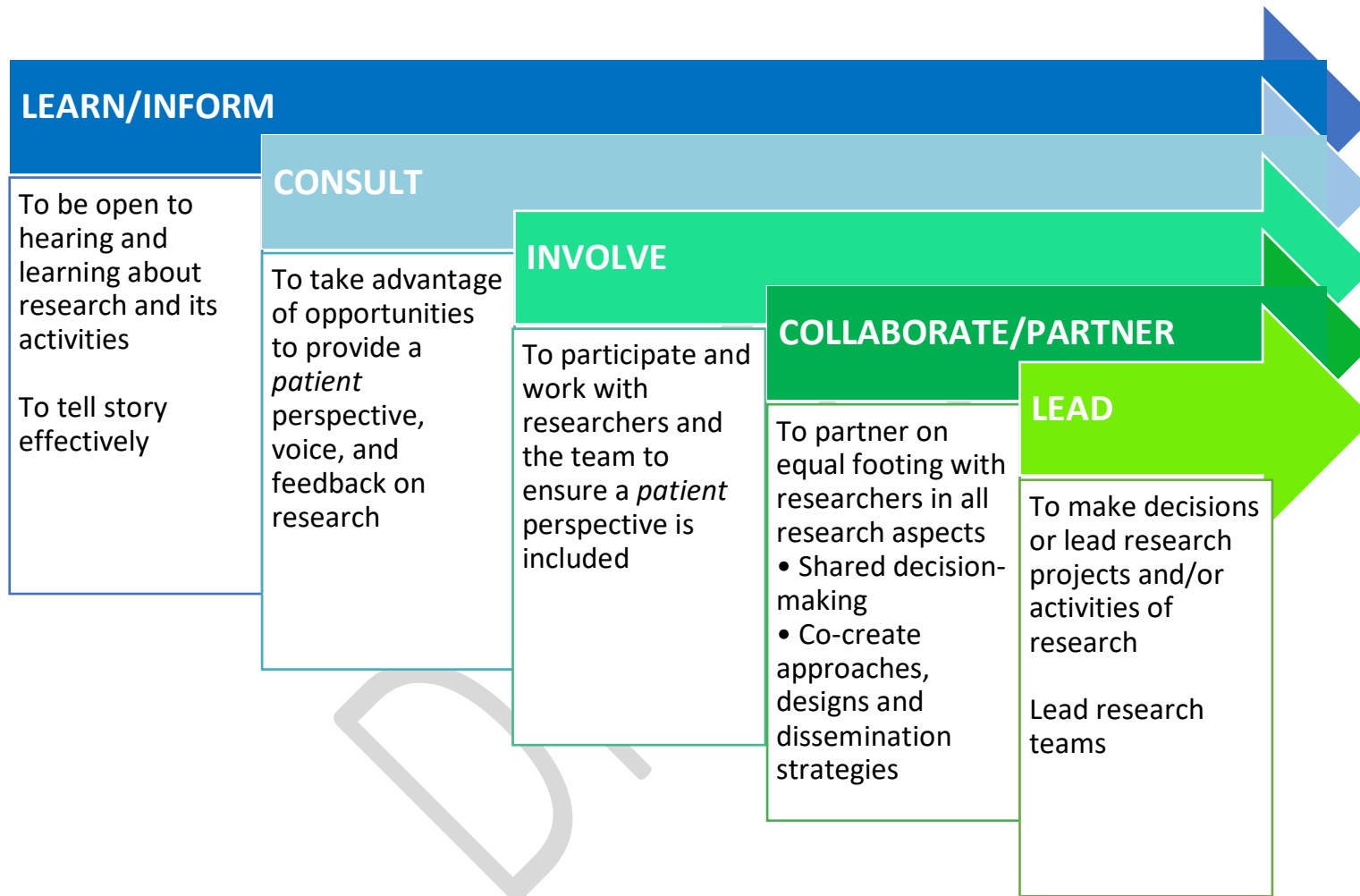


Figure 2. AB SUPPORT Unit PE Platform - Engagement Spectrum for Researchers



(Vandall-Walker & Mason Lai, 2015)

Figure 3. AbSUPPORT Unit PE Platform - Engagement Spectrum for *Patients*



(Vandall-Walker & Mason Lai, 2015)

Competencies are presented for each level of engagement in Tables 1–5. Engagement is meaningful when it is mutually beneficial and considered to be value added for all parties. It is expected that the level and degree of interaction, two-way exchange, and perceived value will intensify as parties move from the level of Learn/Inform to Empower/Lead. Each table presents competencies that are identified and attributed to either the researcher or the *patient*. However, some competencies are not exclusive to one or the other but may be applicable to both researcher and *patient*; for simplicity, these competencies were not listed twice.

In Tables 1–5 the inventory of competencies is grouped according to the spectrum of engagement, but they can also be organized according to following five domains: communication [C], team function [TF], interpersonal or individual [IT], *patient* centredness [PC] and leadership [L]. This is another method to categorize the competencies of *patient* engagement, which is complementary to the IAP2 levels of engagement.

- Communication [C] is a key domain with many components that are critical to meaningful engagement.
- Team function [TF] considers the dynamics of how well individuals work together in a team setting.
- The interpersonal or individual [IT] domain consists of the characteristics, behaviours, or attitudes of each of the team members. The interpersonal or individual domain involves individuals' self-reflections about their own attitudes or behaviours that may impact team functioning and goal attainment.
- *Patient* centredness pertains to the *patient* as a person with lived experiences.
- Leadership consists of the traits or qualities that support and advance *patient* engagement.

In Tables 1–5, beside each competency bullet is a code to identify the domain, as in the following example:

- Ability to use plain language [C]

Some competencies may be applicable to more than one domain, but the code will represent the primary domain.

Table 1. Competency for Learn/Inform Level of Engagement

1. Learn/Inform	
<p>Competency Statement: Researchers and <i>Patients</i> understand this level of engagement as predominantly one-way transmission of information and knowledge as it relates to research activities and projects that are underway, in progress, or completed. Communication is more passive, with less active engagement between sender and receiver.</p>	
<p>Researcher Abilities</p>	<ul style="list-style-type: none"> • Open to questions • Uses plain language when needed (oral and written) [C] • Adapts information to appropriate reading level [C] • Listens, hears and clarifies meaning of questions • Communicates using different media and technology [C] • Aware of diversity of needs [IT]
<p>Patient Abilities</p>	<ul style="list-style-type: none"> • Willing to be informed [C] • Accepts information or material as presented [C] • Desires knowledge and understanding, both superficial and in depth • Understands that some decisions have been made [IT] • Accepts that <i>patient</i> input may not required [IT] • Seeks clarification of unclear information (C)
<p>Tools/Methods</p>	<ul style="list-style-type: none"> • Flyers • News releases • Newsletters • Open houses, meetings • Display boards • Social media: Blogs, Email, Facebook, Twitter
<p>Communication [C], Team Function [TF], Interpersonal or Individual [IT], <i>Patient</i> Centredness [PC], and Leadership [L]</p>	

Table 2. Competency for Consult Level of Engagement

2. Consult		
Competency Statement:		
Researchers and <i>Patients</i> understand this level of engagement as information and opinion seeking with <i>patients</i> invited to provide their perspectives and feedback with acknowledgement of their contribution.		
Researcher Abilities	<ul style="list-style-type: none"> ● Actively listens & hears different perspectives [C] ● Open to critical feedback [IT] ● Open and transparent [IT] ● Explains in plain language [C] and/or asks questions in language congruent with audience [C] ● Speaks confidently in front of others [C] 	<ul style="list-style-type: none"> ● Empathetic [IT] ● Incorporates principles of <i>patient</i> centredness (respect, dignity, information sharing, and participation) [IT] ● Actively seeks <i>patient's</i> ideas/opinions/perspective [IT]
<i>Patient</i> Abilities	<ul style="list-style-type: none"> ● Speaks confidently in front of others [C] ● Open to share lived experiences and ideas clearly [IT] ● Reasonably available as required [IT] ● Provides open and honest feedback [C] 	<ul style="list-style-type: none"> ● Interested in learning more about research [IT] ● Represents his/her own perspective or views [C] ● Identifies that his/her perspective is not representative of others, community, or disease [C]
Tools/Methods	<ul style="list-style-type: none"> ● Focus groups ● Interviews 	<ul style="list-style-type: none"> ● Surveys ● Social Media
Communication [C], Team Function [TF], Interpersonal or Individual [IT], <i>Patient</i> Centredness [PC], and Leadership [L]		

Table 3. Competency for Involve Level of Engagement

3. Involve		
Competency Statement: Researchers and <i>Patients</i> understand this level of engagement as ACTIVE inclusion of <i>patients</i> in any aspect of research.		
Researcher Abilities	<ul style="list-style-type: none"> • Listens actively [C] • Patient [IT] • Establishes productive relationship [TF] • Incorporate patient perspectives [PC] • Clearly articulates roles, responsibilities [TF] • Explores patient’s expectations and motivations [TF] • Matches patient’s expected level of participation to engagement with team [TF] • Prepares and supports patients to be actively involved as research team members [TF] • Establish safe, welcoming environment [PC] • Understands needs for psychological, emotional, and physical safety [PC] • Facilitate conflicting and diverse opinions [TF] 	<ul style="list-style-type: none"> • Inclusive [TF] • Adept at reading non-verbal cues [TF] • Negotiates common goals [C] • Communicate effectively and continuously (closing the loop is critical) [C] • Appreciates all individuals' strengths, contributions, and input [PC] • Understands a patient is not representative of his or her community [PC] • Fosters and encourages diversity [L] • Creative in approaches to involve patients [PC] • Flexible to the barriers, constraints, and personal obstacles [IT] • Accessible and responsive [IT]
<i>Patient</i> Abilities	<ul style="list-style-type: none"> • Listens and respect other perspectives [C] • Patient [IT] • Forms productive relationship [TF] • Identifies and communicate expectations [TF] • Prepared for meetings [IT] • Prepared to invest time and energy [IT] • Works well with others [IT] 	<ul style="list-style-type: none"> • Accepts diverse opinions [IT] • Deals effectively with conflict [TF] • Maintains confidentiality [IT] • Adheres/abides by research ethics protocols [TF] • Understands the research process and requirements [TF] • Understands roles and responsibilities [TF]
Tools/Methods	<ul style="list-style-type: none"> • Workshops • Small intimate group/team meetings • Open dialogue 	<ul style="list-style-type: none"> • World cafés - flexible format for large group dialogue • Charrette - Intensive planning session
Communication [C], Team Function [TF], Interpersonal or Individual [IT], <i>Patient</i> Centredness [PC], and Leadership [L]		

Table 4. Competency for Collaborate/Partner Level of Engagement

4. Collaborate/Partner	
<p>Competency Statement: Researchers and <i>Patients</i> understand this level of engagement is about active partnership where patients are valuable partners and integrated as an essential and equal member of research team.</p>	
<p>Researcher Abilities</p>	<ul style="list-style-type: none"> • Establishes meaningful relationship of mutual trust and understanding [TF] • Integrates <i>patients</i> into research team early in the research process [L] • Establishes mutually agreed upon goals [L] • Co-develops and co-designs research [L] • Shares decision making [L] • Shares all project information [TF] • Intervenes if there is a lack of inclusion, respect, and trust within the team [L]
<p><i>Patient</i> Abilities</p>	<ul style="list-style-type: none"> • Uses partnership language of <u>with</u> <i>patients</i> and not <u>to</u> or <u>for</u> <i>patients</i> [C] • Shares successes and recognition [L] • Acts in role as a mentor or buddy to other researchers seeking to engage <i>patients</i> [L] • Advocates for <i>patient's</i> collaboration in research [L] • Shares collective experiences [C] • Engages continuously [L] • Provides constructive feedback [C]
<p>Tools/Methods</p>	<ul style="list-style-type: none"> • Sees beyond own experiences to the big picture [IT] • Understands research processes and implications [IT] • Can act as an advisor [IT] • Advocates for research [L] • Sees the value of their commitment [IT] • Mentors or trains other <i>patients</i> [L] • Makes decisions [L] • Thinks critically [IT] • Maintains partnership [IT] • Participatory decision making
<p>Communication [C], Team Function [Tf], Interpersonal or Individual [It], <i>Patient</i> Centredness [Pc], And Leadership [L]</p>	

Table 5. Competency for Lead Level of Engagement

5. Lead		
Competency Statement:		
Researchers and Patients understand this level of engagement is the investment of time and resources to build trusting relationships and to promote the shift in research culture where patients are the decision-makers or leading research.		
Researcher Abilities	<ul style="list-style-type: none"> • Implements decisions of patients [IT] • Proceeds with patient advice and recommendations [IT] 	<ul style="list-style-type: none"> • Flexible and/or adaptive [IT] • Supports patient-led research [L] • Act in role as advisor to patient-led research [IT]
Patient	<ul style="list-style-type: none"> • Thinks strategically [IT] • Thinks creatively [IT] • Demonstrates leadership [L] 	<ul style="list-style-type: none"> • Influences others [IT] • Sustains commitment [IT] • Prepared to undertake research [IT]
Tools/Methods	<ul style="list-style-type: none"> • Service contracts • Delegated decisions 	<ul style="list-style-type: none"> • Mock Juries • Patient compacts
Communication [C], Team Function [TF], Interpersonal or Individual [IT], <i>Patient</i> Centredness [PC], and Leadership [L]		

Section 2 – Strengths and Readiness Assessment Tool

To achieve the basic proficiency in the competencies above, orientation, education, and training will be essential. Prior to the development and delivery of education, an assessment of strengths, readiness, and desire to engage is highly recommended. Furthermore, the PROSCI ADKAR Model of Change Management [8] is one change model that can be applied as a component of the strategy and tactics of the PE Platform because the engagement of *patients* in research requires a shift in behaviours, practices, and intention from all parties. The PROSCI ADKAR Model of Change Management is well-known and has been used to facilitate transformational change that is focused on the **people** side of change. While improvements in processes and technology are important elements to advance change, neglecting the people involved with any change will limit the success and expected outcomes.

The Prosci ADKAR Model of Change Management (ADKAR) is based on the following:

- **Awareness** of the need for change
- **Desire** to participate and support the change
- **Knowledge** of how to change
- **Ability** to implement required skills and behaviours
- **Reinforcement** to sustain the change

To supplement the adapted IAP2 spectrum, if ADKAR is adapted to *patient* engagement in health research, the following would apply:

- **Awareness** of the need for *patient* engagement in health research
- **Desire** to participate and support *patient* engagement in health research
- **Knowledge** of how to engage with *patients* (approaches, principles, best practices, training, and education)
- **Ability** to implement and evaluate/monitor engagement strategies, skills, and competencies
- **Reinforcement** of *patient* engagement (benefits realization, evidence, outcomes, funding opportunities)

For the individual researcher or *patient*, it is often the lack of desire or inability to implement that impedes adopting any changes. Hence, a necessary first step is the administration of an assessment tool/questionnaire. Specific statements in the tool have been developed to represent competencies from each level of engagement, although more statements are representative of the upper levels of engagement due to the increased intensity of engagement at these levels. The attached tool will be pilot-tested with select stakeholders.

Strengths and Readiness Assessment Tool

This tool will assist the PE Platform to understand your strengths and to determine the level of engagement that you may be interested in and your readiness to engage.

Part One: Select the best choice to the following statements using the scale 1 to 5, with 1 = Least like you and 5 = Most like you.

Rate the Statements	1	2	3	4	5
1. I understand engagement and the five engagement levels.					
2. I know which engagement level I am interested in.					
3. I have the time to commit to meaningful engagement.					
4. I have the skills and abilities for engagement.					
5. I am able to let others make decisions.					
6. I value when my opinion is sought.					
7. I have experience providing constructive feedback.					
8. I enjoy being involved and part of the solution.					
9. I can clearly communicate my ideas and opinions.					
10. It is important to me that my input is used.					
11. I prefer when others take responsibility to lead or provide leadership.					
12. I respect other perspectives.					
13. I am an effective team player.					
14. I am comfortable with ambiguity.					
15. It is important to me to be open and transparent.					
16. I am comfortable dealing with conflict.					
17. I relate easily to others.					
18. I often seek and embrace change.					
19. I get easily frustrated when I encounter barriers and obstacles.					
20. I seek opportunities to learn new things.					
21. I value the contributions of others.					
22. I thrive in challenging situations.					
23. I am sensitive to the needs of others.					
24. I learn to trust others quickly.					
25. I prefer to collaborate with others instead of performing alone.					

Part Two: Fill in your responses to the following statements.

		Agree	Disagree	Unsure
1.	<i>Patient</i> engagement in research will lead to specific outcomes.			
2.	There are benefits to <i>patient</i> engagement in research.			
3.	Engagement is a one-size-fits-all approach.			
4.	Engagement takes time, resources, and expertise.			
5.	Engagement strategies and tactics are important to learn.			
6.	Engagement requires specific skills, abilities, and behaviours.			
7.	Collaboration and partnership are important aspects of engagement.			
8.	Changes in practice and behaviours will not lead to meaningful engagement.			
9.	Challenges and barriers with <i>patient</i> engagement in research can be overcome.			
10.	<i>Patient</i> engagement in research is the future.			

DRAFT 5

Key for Strengths and Readiness Assessment Tool

The assessment tool was developed to allow for quick reference or at-a-glance interpretation and simple assessment of an individual's strengths, level of engagement, and as a pulse check on readiness. The tool has two parts: Part one primarily focuses on assisting with the identification of the engagement level that may be appropriate and Part two provides an indicator of strengths, readiness, understanding, and opportunity.

In Part one, the responder identifies how close the statement relates to him or her. For the key, the scale of 1 to 5 is used in two different ways: as an indicator for general knowledge and readiness and as the representation of the engagement spectrum.

Statements #1 to #4 are included to assess general readiness and basic knowledge. The higher the response number the likelihood that the *patient* or researcher has some knowledge and readiness to engage. The remainder of the statements are representative of the different engagement levels and selected competency requirements.

To determine the level of engagement that may be of interest involves a quick review of the pattern of responses. Count the responses for statements #5 to #25 but do not include #1 to #4. Add up the numbers from each column and multiply the number of responses in that column by the multiplier. The highest number in a specific column would indicate a specific engagement level as a starting point for planning engagement. The *patient* or researcher is not necessarily limited to that level but could proceed with the upper levels of engagement if comfortable and equipped to do so.

This tool is meant as a guide for discussion with the *patient* or researcher. It is not a definitive assessment of the level at which the *patient* or research should engage. It also provides an opportunity to identify and commend the strengths an individual brings to engagement activities. The tool has been created as a way of balancing the art and science of engagement. Testing of this Strengths, Engagement and Readiness Tool is highly recommended along with a discussion with the *patient* or researcher to validate their strengths, interest, and/or capability.

Sample Scoring of Strengths and Readiness Assessment Tool

Scoring the sample tool below shows the respondent may be interested in engaging at the Involve level with the potential possibility of engaging at the Collaborate level.

Part One: Select the best choice to the following statements using the scale 1 to 5, with 1 = Least like you and 5 = Most like you.

Rate the Statements	1	2	3	4	5
1. I understand engagement and the five engagement levels.			X		
2. I know which engagement level I am interested in.		x			
3. I have the time to commit to meaningful engagement.		x			
4. I have the skills and abilities for engagement.	x				
5. I am able to let others make decisions.				x	
6. I value when my opinion is sought.				x	
7. I have experience providing constructive feedback.				x	
8. I enjoy being involved and part of the solution.				x	
9. I can clearly communicate my ideas and opinions.			x		
10. It is important to me that my input is used.				x	
11. I prefer when others take responsibility to lead or provide leadership.			x		
12. I respect other perspectives.					x
13. I am an effective team player.			x		
14. I am comfortable with ambiguity.		x			
15. It is important to me to be open and transparent.				x	
16. I am comfortable dealing with conflict.			x		
17. I relate easily to others.				x	
18. I often seek and embrace change.			x		
19. I get easily frustrated when I encounter barriers and obstacles.		x			
20. I seek opportunities to learn new things.				x	
21. I value the contributions of others.				x	
22. I thrive in challenging situations.			x		
23. I am sensitive to the needs of others.			x		
24. I learn to trust others quickly.			x		
25. I prefer to collaborate with others instead of performing alone.				x	
	#R x 5	#R x 4	#R x 3	#R x 2	#R x 1
Start counting responses after line #4, do not include the first 4 statements in the count	0 x 5 = 0	2 x 4 = 8	8 x 3 = 24	10 x 2 = 20	1 x 1 = 2
Total	Learn/Inform	Consult	Involve	Collaborate	Lead

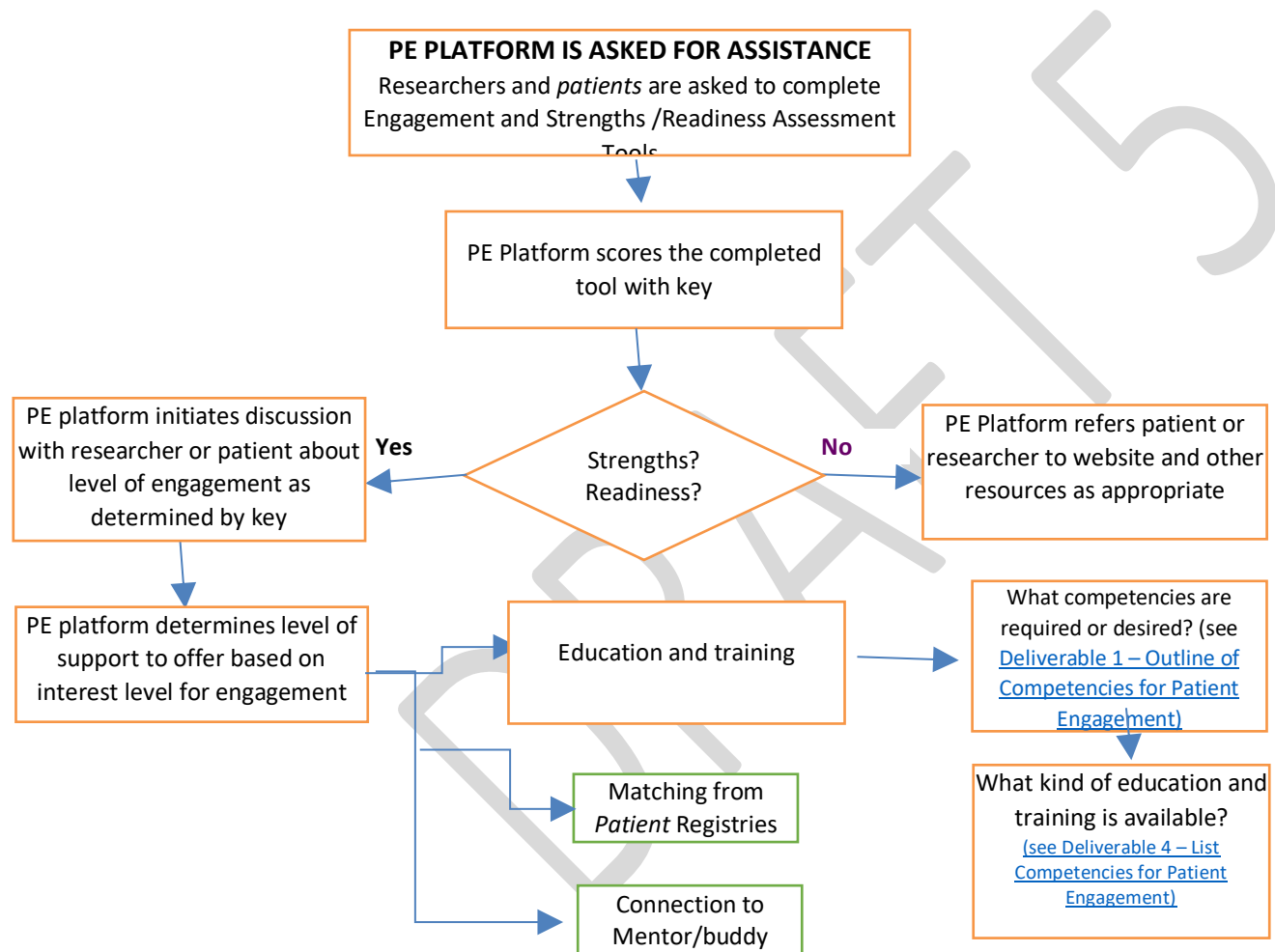
Part two of the engagement and readiness tool provides further information about readiness, understanding, and opportunity. The statements are meant to elicit responses that demonstrate receptiveness to engagement, value attributed to engagement, and optimism toward engagement.

It is expected that the respondent choose Agree or green light for the following statements: #1, #2, #4, #5, #6, #7, #9, and #10. It is expected that the respondent choose Disagree or red light for statement #3 and #8. If the responses do not match exactly, it may indicate that the respondent may not be ready or have the desire to engage. Further consultation and support may be required.

Part Two: Fill in your responses to the following statements.

	Agree	Disagree	Unsure
1. <i>Patient</i> engagement in research will lead to specific outcomes.			
2. There are benefits to <i>patient</i> engagement in research.			
3. Engagement is a one-size-fits-all approach.			
4. Engagement takes time, resources, and expertise.			
5. Engagement strategies and tactics are important to learn.			
6. Engagement requires specific skills and abilities.			
7. Collaboration and partnership are important aspects of engagement.			
8. Changes in practice and behaviours will not lead to meaningful engagement.			
9. Challenges and barriers with <i>patient</i> engagement in research can be overcome.			
10. <i>Patient</i> engagement in research is the future.			

Figure 4. AbSPORU Patient Engagement Platform Flow Chart



Section 3 – Outline for Orientation, Education, and Training in *Patient* Engagement in Research

A key recommendation is that if possible, certain modules or components of education and training are offered and delivered with both *patients* and researchers as class participants together to begin the process and modelling for effective engagement. It has been cited by Involve and the National Institute of Health Research [9] that the interaction, learning, and relationship building occurs with co-participation in education and training opportunities.

The delivery of education and training should take into consideration the individual preferences and needs of the adult learner. While in-class, facilitated learning is beneficial because it allows interaction, networking, and opportunities to address questions, other modes/methods of education delivery should be available as well. Many learners prefer opportunities for self-directed education through eLearning modules or webinars so that the time to dedicate is not limited to a prescribed classroom schedule. Variety and flexibility in delivery methods for education and training are recommended.

Some of the courses/modules have been classified according to audience or stakeholder category. It may be appropriate that some courses/modules are applicable to the other stakeholder or audience not identified. Also courses/modules/content may be selected by the learner as part of their own individual learning plan or goals. Also it is recommended that a training or learning needs assessment tool be used, if appropriate, to help learners and PE Platform determine the education and training required.

However, it is recommended that the PE Platform do not limit education and training to courses or modules. Applicable content and material can be shared with learners in many ways such as short vignettes, storyboards, handouts, learning guides, You-Tube videos, case studies, and communities of practice, for example, mentoring and train-the trainer.

CIHR has three pilot modules for their curriculum in development that would be part of the education and training available to the PE Platform. The three modules have their own extensive learning objectives:

Module 1 – Patient-Oriented Research
Module 2 – Fundamentals of Health Research in Canada
Module 3 – Building Partnerships and Consolidating Teams

While the three modules being developed by CIHR through the various SPOR SUPPORT units should be part of the overall orientation, education and training for those researchers and *patients* working with the PE Platform, other learning content should be added either as core requirements or as supplemental learning. Much of the learning content described below is recommended for the learner to achieve the competencies identified in Tables 1–5.

Table 6 is a quick reference chart to see that the learning content recommended would be appropriate for each engagement level. A brief description of each course or module follows with the specific learning objectives.

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Table 6. Recommended Outline of Education for *Patients* and Researchers

Applicable Level of Engagement				
(Patients and Researchers)				
Learn/ Inform	Consult	Involve	Collaborate/ Partner	Lead
	Building Research Relationship Workshop	Building Research Relationship Workshop	Building Research Relationship Workshop	Building Research Relationship Workshop
		What's In It For Me (WIIFM)	What's In It For Me (WIIFM)	What's In It For Me (WIIFM)
	Communication Skills for Beneficial Engagement	Communication Skills for Beneficial Engagement	Communication Skills for Beneficial Engagement	Communication Skills for Beneficial Engagement
		Advisory versus Advocacy	Advisory versus Advocacy	Advisory versus Advocacy
		Conflict Resolution and Team Dynamics	Conflict Resolution and Team Dynamics	Conflict Resolution and Team Dynamics
		Leadership	Leadership	Leadership
Introduction to <i>Patient</i> Engagement and <i>Patient</i> Centredness	Introduction to <i>Patient</i> Engagement and <i>Patient</i> Centredness	Introduction to <i>Patient</i> Engagement and <i>Patient</i> Centredness	Introduction to <i>Patient</i> Engagement and <i>Patient</i> Centredness	Introduction to <i>Patient</i> Engagement and <i>Patient</i> Centredness
Diversity or Cultural Awareness/Safety	Diversity or Cultural Awareness or Cultural Safety	Diversity or Cultural Awareness or Cultural Safety	Diversity or Cultural Awareness or Cultural Safety	Diversity or Cultural Awareness or Cultural Safety
		Facilitation	Facilitation	Facilitation
		Evidence-based Learning	Evidence-based Learning	Evidence-based Learning
		Introduction to Research Basics "What Do Researchers Do?"	Introduction to Research Basics "What Do Researchers Do?"	Introduction to Research Basics "What Do Researchers Do?"
		Research Ethics, Privacy, and Regulations/Acts	Research Ethics, Privacy, and Regulations/Acts	Research Ethics, Privacy, and Regulations/Acts
		Training for specific roles/functions, e.g., data collection, analysis, dissemination of research findings	Training for specific roles/functions, e.g., data collection, analysis, dissemination of research findings	Training for specific roles/functions, e.g., data collection, analysis, dissemination of research findings

Learning Content Details

A. Building a Research Relationship Workshop

The workshop will start the relationship-building process and help to facilitate *patient* engagement and communication. It should promote individual and group dynamics on what it means to work together and establish the foundations and principles required for *patient* engagement in research.

At the end of the workshop, the learner will be able to:

- Describe the guiding principles and goals of SPOR.
- Identify the primary elements of effective relationships.
 - Credibility
 - Authenticity
 - Transparency
 - Openness
 - Empathy
 - Communication
- Identify the Alberta PE Platform levels of engagement and the commitment (Figures 1 and 2).
- Identify and understand the benefits, challenges, and risks to engagement.
- Explain the roles and responsibilities of those involved.
- Create mechanisms or opportunities to continue relationship beyond workshop/classroom.
 - Tactics – randomized coffee trials

This learning content will start to build competencies in the domains of communication, interpersonal, and team function that can apply to all levels of engagement but specifically with Inform, Consult, and Involve.

B. What's In It For Me (WIIF)

An information session or handout or brief vignette can be provided to describe and illustrate the benefits of *patient* engagement in research for both perspectives—*patients* and researchers. It is an opportunity to present a universal compact or agreement of what meaningful engagement would entail. This content could be delivered early as part of the recruitment process for advisors and as a prerequisite for researchers who may be laggards in supporting *patients* in research.

The learner will be able to:

- Identify the Alberta PE Platform guiding principles.
- Express the benefits of engagement as it pertains to research.
- Express the opportunities and benefits for *patients*.
- Express the opportunities and benefits for researchers.
- Celebrate the skills and experience they have and what they could contribute to research.

This learning content will support change adoption and, similar to the Building Research Relationship Workshop, it starts to build competencies in communication, interpersonal, and team function.

C. Communication Skills for Beneficial Engagement

A fundamental and foundational course that is appropriate for all audiences to enhance or build communication skills. It is often taken for granted that we communicate well with each other, but effective communication is a two-way process that requires practice and refinement. This course or module will increase communication to build better relationships to support engagement. A classroom setting is recommended in order to allow for the interaction, role play, and simulation exercises.

At the end of the course/module, the learner will be able to:

- Articulate the importance of active listening and the steps required.
- Demonstrate a broad range of relevant communication skills and strategies.
- Judge when communication is not working and how to take the appropriate action or steps.
- Distinguish the communication needs required for circumstances, situations/content, and audiences.

This course/module will facilitate attaining proficiency of many competencies in all levels of engagement.

D. Advisory versus Advocacy

This course/module should cover governance and structures related to *patient* engagement in research. It should highlight the different types of opportunities and the distinction of the advocate versus advisor role. This content could be offered early in the recruitment process to help support potential advisors in their decision to become involved in research in an advisory capacity. While the terms advocacy and advisory have a few functional similarities, for the purposes of the PE Platform and research the differences are significant. Advocates plead the cause of another while *patient* advisors lend their voice and experience by partnering for change. The material can also be delivered as e-learning, vignette, or printed learning.

At the end of the course/module, the learner will be able to:

- Identify and articulate the difference between an advisor and an advocate.
- Identify governance structures and understand the processes and criteria for creating advisory structures.
- Appreciate the commitment of time and resources for recruitment.
- Understand the processes for recruitment and support required.

This content should apply to the competencies within the spectrum of Collaborate/Partner and Empower.

E. Conflict Resolution and Team Dynamics

This course/module should provide knowledge of conflict resolution because it is an important component of effective collaborative processes. Conflict, or the potential for it, should be expected and managed appropriately to support positive, healthy team functioning. The pilot module from CIHR contains elements of conflict resolution training. At the end of the course/module, the learner will be able to:

- Identify and understand conflict management techniques.
 - For example, interest-based relational (IBR) approach
- Apply techniques in scenario-based activities.
- Identify the steps and processes in resolving conflict.
- Assess team effectiveness.
- Build an effective team. This content should apply to the competencies with the level of Involve and higher.

This content should apply to the competencies with the level of Involve and higher

F. Leadership

This course/module is recommended to encompass the need for change and transformation within research. As *patient* engagement is a relatively new and foreign concept, practicality and leadership are required to help guide and position *patient* engagement in research. This course/module should help to build or enhance those skills in both *patients* and researchers.

At the end of the course/module, the learner will be able to:

- Identify what a leader is and describe how to become one.
- Understand the various leadership styles.
- Identify power differentials and status.
- Identify different leadership theories and techniques.
 - Four-Factor Theory of Leadership (Bowers & Seashore, 1966) [10]
 - Providing personal support
 - Encouraging teamwork (“Interaction Facilitation”)
 - Focusing on goals (“Goal Emphasis”)
 - Helping people work effectively (“Work Facilitation”)
- Exercise the learner’s own leadership skills.

This content is appropriate for any level of engagement but will help facilitate attaining proficiency in the leadership domain.

G. Introduction to *Patient* Engagement and *Patient* Centredness

This course/module is important content and learning for those who have not worked with *patients* or have the understanding of patient engagement. It is appropriate for all levels of engagement. This course should be mandatory education and a precursor for the Diversity/Cultural Awareness or Cultural Safety course.

At the end of this course/module, the learner will be able to:

- Identify the principles and pillars of *patient*-centred care according to the Institute of Patient and Family Centered Care (IPFCC).

- Understand the difference between *patient* engagement and *patient* centredness.
 - Understand and apply different strategies and approaches for *patient* engagement (e.g., focus groups, interviews, advisory councils, networks).
 - Differentiate between *patients* and their perspectives, needs, and preferences.
 - Appreciate the value and benefits of having *patients* engaged in research.
 - Construct or design research proposals or projects that involves or integrates *patients*.
- The course will support the attainment of competencies in the level of Consult and higher.

H. Diversity or Cultural Awareness or Cultural Safety

The learning content of this course/module is important to build competencies that meet the needs of engaging individuals from different backgrounds including cultural, ethnic, or diverse beliefs, perspectives, orientations, and world views. This material is appropriate for any level of the engagement spectrum.

At the end of this course/module, the learner will be able to:

- Recognize own belief system and how it might impact interactions with others with different culture, beliefs, etc.
- Recognize the value of the individual first.
- Identify own limitations (comfort, knowledge) and know where to seek assistance.
- Practice self-reflection and self-awareness.

This content should support and help build better working relationships whether they are partnerships or consults. The knowledge gained should enhance communication, promote respect and sensitivity, and lend itself to improved team dynamics.

I. Facilitation

Facilitation is an added benefit and skill that would be useful to support group/team settings and activities and to help group/team set common goals and achieve outcomes. To facilitate means to make easy or to ease a process.

At the end of this course/module, the learner will be able to:

- Describe the art of facilitation and how to use it to assist dialogue and group functioning.

- Understand the role of the facilitator.
- Design and plan the group process.
- Guide and control the group process.
- Build comfort and experiential learning by applying facilitation methods and techniques in classroom setting with interactive activities.

This content will help with driving success in patient engagement in research as the facilitator takes an objective stance to move the group goals forward. Someone with this role could attain the competencies identified in the level of Involve and higher.

J. Evidence-Based Learning

As with many different types of learning styles, a course that meets the needs to demonstrate the benefits of *patient* engagement by providing the learner the necessary evidence would be recommended. This content would be self-directed learning through the availability of seminal literature and articles and with opportunities to connect with individuals who have the experience of benefitting from patient engagement. Two examples of seminal literature that should be a must read are Domecq, J.P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., et al. (2014) [\[11\]](#) and Biomedical Research Institute Patient-Centered Comparative Effectiveness Research Center (2013) [\[12\]](#).

The learner through self-learning and networking will be able to:

- Understand the impacts of *patient* engagement in research.
- Understand the benefits and value to engaging with *patients*.
- Network with key individuals or groups (PCORI, community of practices, *patient* research networks).

This learning content will support attainment of some competencies from the level of Involve or higher because of “buy-in” and change adoption.

K. Introduction to Research Basics “What Do Researchers Do?”

This course is appropriate for any level of engagement and is applicable to anyone interested in learning about research, its process, etc. This content also covered in CIHR pilot module.

At the end of this course/module, the learner will be able to:

- Identify the different types of research conducted.
- Identify and understand the research process and terminology.
- Understand the stages of planning, proposal, funding, execution – dissemination, KTE knowledge, transfer and exchange.
- Identify the roles and responsibilities of doing research.
- Understand the role of the principal investigator and the importance of consent and ethics (basics only because Ethics is a complete course on its own).
- Describe the benefits and challenges of doing research.
- Understand the expectations of *patients* in research.

After this course/content, the learner will be able to achieve competencies within the level of Involve or higher.

L. Research Ethics, Privacy and Regulations/Acts

This learning content could be delivered as self-directed learning via e-learning. Content could be divided into three separate mini-modules. It is most appropriate for the level of Involve, Collaborate/Partner, and Empower/Lead. Some of this material is also available via the CIHR pilot module.

At the end of this course/module, the learner will be able to:

- Identify the ethics process (Health Research Ethics Boards, ARECCI).
- Distinguish between ethical and non-ethical practices.
- Identify the applicable security and privacy legislation, e.g., *Health Information Act (HIA)*, *Freedom of Information and Protection of Privacy Act (FOIPP)*.
- Identify pertinent regulations, guidelines, and policies (dependent upon the type of research, specifics of research project/group).

M. Specialized Training

This type of learning or education should be offered based on need, interest, and research design, and is applicable only for the level of Involve, Collaborate/Partner and Empower/Lead. This content would be customized to the role required in *patient* engagement in the areas such as data gathering (surveys, focus groups, interviewing, ethnography), data analysis (quantitative and qualitative), and dissemination of research findings (research paper writing and publication).

At the end of this course/module, the learner will be able to:

- Identify the different methods to gather data.
- Understand and apply the best-suited method for the research question.
- Conduct data collection.
- Understand the differences between quantitative and qualitative analysis.
- Identify statistical methods and tools.
- Support analysis with theming and *patient* perspective.
- Identify the process and criteria for research papers and publication.
- Identify opportunities for dissemination of research.
- Identify role that *patients* play in dissemination.
- Contribute to writing of the report/publication.

This customized content offering lends itself to team integration of *patients* and empowering *patients* with the knowledge and skills to add tangible value and results to research. The recommended outline for education and training shown in Table 6 and the competencies identified in Tables 1–5 are inherently linked. If a *patient* or researcher needs support and lacks the skills and/or abilities identified, the potential learning that the PE Platform could offer will help to attain the desired competency. For example at the Involve level, a *patient* competency of “understand the research process and requirements” necessitates that the *patient* have knowledge of research basics and research cycle. A *patient* cannot attain understanding without first obtaining the knowledge through education and learning.

Figure 4 illustrates the knowledge that would be acquired based on the education and training from PE Platform or elsewhere. Also listed are the general skills that would be acquired (not specific to any level of engagement). Collectively, these all support for

successful performance. As mentioned previously, attitudes (many of which are listed under the domain of interpersonal) are difficult to change and can lead to poor outcomes. However, attitudes can be influenced and adjusted with a focus on the individual and change management tactics. Relationships, persuasion, and evidence are part of the solution as well. Often peer pressure, trust in key individuals, or the inability to resist the tide of change may lead to attitudinal amendments leading to success. It is beyond the scope of this document to address the topic of attitudes other than to make note of some of the influences in attitudes.

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Figure 4. Knowledge Areas and Skills for Researchers and *Patients*

	Researchers	<i>Patients</i>
Knowledge Areas	<ul style="list-style-type: none"> • Principles and goals of <i>patient</i> centredness • Engagement strategies and tactics • Recruitment and selection • Team effectiveness • Cultural safety and diversity • Governance and structures • Leadership styles and approaches • Best practices and evidence of <i>patient</i> engagement • Power and status differentials • Consensus building, goal setting, and shared decision making • <i>Patient</i> Research Networks • <i>Patient</i> Advisory groups • Applicable regulations, acts (HIA, FOIP) and associations (CIHR, etc.) 	<ul style="list-style-type: none"> • Research basics and research cycle • Ethics • Security, privacy, and confidentiality • Quantitative and qualitative research methods • Data collection and analysis • Interviewing strategies and techniques • Leadership styles and approaches • Cultural safety and diversity • Best practices and evidence of <i>patient</i> engagement • Team effectiveness • Knowledge translation and dissemination • Broad health system • Advisory versus advocacy • Applicable regulations, acts (HIA, FOIP) and associations (CIHR, etc.) • <i>Patient</i> Research Networks
Skills and Attributes	<ul style="list-style-type: none"> • Communication skills • Conflict resolution skills • Time management and organizational skills • Team building • Strong human relation skills • Facilitation skills • Tact and diplomacy • Empathy • Creativity • Problem-solving skills • Training and coaching • Networking and connector skills 	<ul style="list-style-type: none"> • Communication skills • Presentation and public speaking skills • Working within a team and independently • Time management and organizational skills • Tact and diplomacy • Empathy • Problem-solving skills • Creativity • Training and coaching • Networking and connector skills

Section 4 – List of Currently Available Education and Training

There are existing modules, learning content, and curriculum available that meets the specific education requirements for the PE Platform such as the CIHR pilot modules.

For additional content beyond the CIHR modules, collaborate or partner with specific organizations for the development or use of existing programs and/or content. The organizations in the United Kingdom are highly recommended for their educational opportunities for both researchers and patients. The National Co-ordinating Centre for Public Engagement (NCCPE), INVOLVE, and Vitae appear to have well-developed content to support education of researchers and patients or public in research.

Another option is partnering with the University of Alberta's Women and Children's Health Research Institute (WCHRI) and the Faculty of Extension for courses/training that may be available within the areas of community engagement and community-based research. WCHRI has a patient engagement arm, and they support researchers with patient involvement. The University of Montreal Faculty of Medicine Partnership and Collaboration Unit would be another partner worth connecting with for content and partnership.

Seminal literature document from PCERC (Patient-Centered Comparative Effectiveness Research Center) listed above has a wealth of information and a good tool to use.

CIHR commissioned an environmental scan and discussion of the findings [2, 3]; this document is detailed and robust. Table 7 presents a list of currently available education or training that would be supplemental to the CIHR documents. Where information was available as to course description, course objectives, and any logistical information as to delivery method or cost, it was included in the table. As well, the applicable audience, applicable level of engagement, and competency domains were identified based on speculation. The course/module or learning content needs to be validated or verified as to how successfully it fits with these three categories. Contact and consultation with the organizations about their educational offerings would be a recommended next step.

Table 7. List of Currently Available Education and Training

KEY: Course – C Module - M Workshop - W Webinar - Wb Online - O					
EDUCATION CONTENT TYPE	WHO OFFERS IT	CONTENT DESCRIPTION AND DETAILS (COURSE OBJECTIVES, ETC., IF AVAILABLE)	APPLICABLE AUDIENCE	APPLICABLE ENGAGEMENT	COMPETENCY DOMAINS
Interprofessional Health Team Development (C)	Health Sciences Education and Research Council, University of Alberta	Course prepares students for the challenges of their future work environments by developing their skills in interprofessional communication, collaboration, role clarification, and reflection.	<i>Patient and Researchers</i>	Involve and higher	Communication, Team function
Facilitation (W)	Health Sciences Education and Research Council, University of Alberta	Three workshops to <ul style="list-style-type: none"> ▪ build core competencies, core concepts, and learning outcomes related to interprofessional team process ▪ increase participant confidence in selecting and employing co-facilitation, modelling, and debriefing strategies ▪ increase participant skill in assessing team standardized patient interviews and individual and team student reflections 	<i>Patient and Researchers</i>	Involve and higher	Communication, Team function
Culturally Safe and Competent Health Care (E)	Dr. Gina Higginbottom, Canada Research Chair in Ethnicity and Health, U of A	Providing Culturally Safe and Competent Health Care – A self-directed workbook and digital resource which she and her colleagues developed. This interactive electronic web-based learning resource originally is designed to assist nursing students to enhance their understanding and application of cultural competence and cultural safety but has	<i>Patient and Researchers</i>	Inform and higher	Communication, Patient Centredness, and Interpersonal

		transferability for all health care professionals.			
Citizen Engagement and Consultation (C)	Faculty of Extension, University of Alberta	Focuses on practical tools that support and guide the interactions between councils, administration, media, and public. Different approaches will be discussed for municipal and regional land use planning initiatives, which promote effective, democratic engagement and consultation with public spheres.	Patient and Researchers	Involve and higher	Communication, Leadership
Methods of Community-Based Research (C)	Master of Arts program in Community Engagement, Faculty of Extension, UofA	An introduction to research methodology, which broadly includes quantitative, qualitative, and mixed methods. Research design, formulation of research questions, selecting appropriate methods, sampling, data analysis, and knowledge mobilization are included. This course is designed as a seminar; while some classes will be structured, the intent is for participants to learn from each other's experiences and research examples.	<i>Patient</i>	Involve and higher	Team function,
Theory and Practice in PaCER (C)	Program of Patient and Community Engagement Research (PaCER), University of Calgary	<ul style="list-style-type: none"> • History of PPE, Citizen research, Knowledge utilization and uptake • Qualitative research, Phenomenology, Participatory Action Research • Salutogenesis and other health promotion and determinants of Health constructs • Specific methods (field work, interviews and questionnaires, focus groups, narratives) 	<i>Patients</i>	Involve and higher	Team function, Leadership

Making Sense of Research and Evidence (Wb)	Cochrane	An interactive online course using examples from dementia research. The materials are designed to encourage involvement and participation in clinical-based research by health care consumers (patients, families, etc.).	<i>Patient</i>	Involve and higher	Communication, Team function, Leadership
Understanding Evidence-Based Healthcare: A Foundation for Action (Wb)	Cochrane	<p>This web course has been created by the United States Cochrane Center as part of a project undertaken by Consumers United for Evidence-Based Healthcare (CUE). It is designed to help consumer advocates understand the fundamentals of evidence-based healthcare concepts and skills. Registration is open and free of charge. Participants are encouraged to finish the course in three months. We recommend that participants complete only 1–2 modules at a time.</p> <p>Course Objectives: To provide consumer advocates with the tools they need to:</p> <ul style="list-style-type: none"> • Successfully navigate the world of medical information • Critically appraise research studies • Influence the creation of responsible public policy in healthcare • Help the people they serve to make healthcare choices based on the best available evidence <p>Course Description: In these six modules, we will illustrate key concepts with compelling real-world examples, covering the following topics and issues. Run times do not take into account interruptions or a second review of selected slides.</p> <ul style="list-style-type: none"> • Module 1. INTRO: What is evidence-based 	<i>Patient</i>	Involve and higher	Communication, Interpersonal, Team function

		<p>healthcare and why is it important? (45 minutes)</p> <ul style="list-style-type: none"> • Module 2. ASK: The importance of research questions in evidence-based healthcare. (40 minutes) • • Module 3. ALIGN: Research design, bias, and levels of evidence. (1 hour) • Module 4. ACQUIRE: Searching for healthcare information. Assessing harms and benefits. (1 hour 10 minutes) • Module 5. APPRAISE: Behind the numbers: Understanding healthcare statistics. Science, speed, and the search for best evidence. (1 hour 20 minutes) • Module 6. APPLY: Critical appraisal and making better decisions for evidence-based healthcare, determining causality. (1 hour) 			
TRIC (Translating Research into Care) Workshop	Maritime SPOR Support Unit	Learning strategies to incorporate the patient voice or including patients in research.	Researchers	Consult and higher	Communication
Cultural Competency Training (W)	Aboriginal Health, Alberta Health Services	Specifically focus to bring awareness and understanding of Aboriginal culture and need for cultural safety and competence related to communication, expectations, traditions, etc.	Both	Inform and higher	Communication, Interpersonal
Patient Engagement 101 (M)	Engagement and Patient Experience, Alberta Health Services	Web-based module that teaches the definition of patient engagement and what it is and the value of patient voice and perspective at the planning table.	Researcher	Consult and higher	Communication, Interpersonal, Leadership

Patient-Centred Care 101 (M)	Engagement and Patient Experience, Alberta Health Services	Web-based module that teaches the principles and philosophy of patient-centred care, and the needs and expectations of patient of their health experience.	Researchers	Inform and higher	Communication, Team function, Leadership, Patient centredness
IAP2 Training (W)	Delaney and Associates	<p>Consulting firm specializing in engagement and IAP2 training that offers workshops</p> <p>The three sessions focus on: engagement, experience, and relations, but all three come together to provide a comprehensive appreciation of how to move to a more patient- and community-centred approach to health care planning and delivery.</p> <p>Best practices in the area of engagement based upon the well-established methodology from the International Association for Public Participation (IAP2)</p> <p>Tools to create an authentic patient, family, and community engagement process in your organization or improve the quality of your current engagement efforts.</p> <p>Information on Patient/Family Advisory Councils (PFAC)</p>	Both	Inform and higher	Communication, Leadership, Patient centredness
Relational Practice (C)	Thompson River University	This course is designed to advance the relational knowledge and skill of health professionals. It emphasizes concepts such as communication, leadership, interprofessional practice, teaching and learning, diversity, power, and the client as a person, family, and community.	Both	Consult and higher	Communication, Interpersonal, Leadership

<p>Multiple topics: Research Ethics, Privacy and Confidentiality, Conflicts of Interest (Wb)</p>	<p>Tri-Council Policy Statement (TCP2) (CIHR, Natural Sciences and Engineering Research Council, (NSERC) and Social Science and Humanities Research Council (SSHRC)) Government of CA</p>	<p>The TCPS 2 Tutorial - Course on Research Ethics (CORE) CORE provides an applied approach to the guidance provided in TCPS 2. This self-paced course is a media-rich learning approach experience that features interactive exercises and multidisciplinary examples. CORE consists of eight modules ranging from Core Principles to Research Ethics Board (REB) Review. It is designed primarily for the use of researchers and REB members – though anyone may take this course.</p>	<p>Both</p>	<p>Involve and higher</p>	<p>Communication, Team function</p>
<p>Multiple topics: Communication Essentials for Patient- and Family-centred Care; (W)</p>	<p>Institute for Patient- and Family-Centered Care (IPFCC)</p>	<p>Webinars available from IPFCC cost per connection per topic of \$199 USD. Health care professionals and clinicians who want to learn more about the basics of integrating patient- and family-centred care and building partnerships with patients and families, program coordinators charged with implementing patient- and family-centred initiatives, and patient and family leaders serving in an advisory role. Webinar objectives:</p> <ul style="list-style-type: none"> • Learn effective communication strategies, including Careboard Conversations and the Heart-Head-Heart Communication Model, to jumpstart trusting relationships. • Identify seven concrete skills to personalized care, communicating with empathy, and patient and family engagement. • Review strategies for engaging the health care team in strengthening communication skills to achieve better patient outcomes and receive higher patient satisfaction scores. 	<p>Researcher</p>	<p>Consult and higher</p>	<p>Communication, Interpersonal</p>

<p>Creating Patient and Family Advisory Councils (W)</p>	<p>Institute for Patient- and Family-Centered Care (IPFCC)</p>	<p>Webinar objectives:</p> <ul style="list-style-type: none"> • Identify first steps to create an effective advisory council, including recruiting and preparing advisors and staff in how to participate in collaborative partnerships. • Discuss approaches that foster a successful beginning, such as defining council structure, developing the agenda and programmatic efforts, preparing for challenging issues, and celebrating successes. • Review useful resources and tools that will guide you in developing and maintaining your council. 	<p>Both</p>	<p>Collaborate/ Partner and higher</p>	<p>Communication, Team function, Leadership</p>
<p>Growing Your Skills as a Patient and Family Advisor – Strategies for Strengthening Collaboration (W)</p>	<p>Institute for Patient- and Family-Centered Care (IPFCC)</p>	<p>Webinar objectives:</p> <ul style="list-style-type: none"> • Identify strategies to strengthen effectiveness as a patient or family advisor. • Examine opportunities to grow advisor partnerships into new areas. • Discuss challenges facing advisors and solutions to address these challenges. • Explore ways engage social media in collaboration efforts. 	<p>Patient</p>	<p>Collaborate/ Partner and higher</p>	<p>Communication, Team function, Leadership</p>
<p>Promising Practices of Meaningful Engagement in the Conduct of Research (W)</p>	<p>Patient-Centered Outcomes Research Institute (PCORI)</p>	<ul style="list-style-type: none"> • Webinar http://encore.meetingbridge.com/MB005418/130919/http://encore.meetingbridge.com/MB005418/130919/http://encore.meetingbridge.com/MB005418/130919/ • Addresses what is engagement in research? <p>Webinar objectives:</p> <ul style="list-style-type: none"> • To learn successful PCORI engagement practices in all stages of research • To address major concerns and barriers • To inform public about involvement with PCORI 	<p>Both</p>	<p>Consult and higher</p>	<p>Communication, Team function, Leadership</p>

Patient Engagement Videos	Health Affairs	<p>Partnership between Health Affairs and PCORI to produce three videos about ways patients and practitioners are incorporating patient engagement in health care decisions.</p> <ul style="list-style-type: none"> • http://www.healthaffairs.org/events/2013_02_06_patient_engagement/ • http://www.healthaffairs.org/events/2013_02_06_patient_engagement/ • http://www.healthaffairs.org/events/2013_02_06_patient_engagement/ • http://www.healthaffairs.org/events/2013_02_06_patient_engagement/ 	Both	Consult and higher	Communication, Team function, Leadership
Maximizing Patient Engagement Through Effective Communication (W)	Sutter Health	<p>Webinar objectives:</p> <ul style="list-style-type: none"> • Examine the principles of patient activated learning and adult learning. • Describe one way to assess patient learning. • Discuss health literacy and its relationship to patient engagement. • Maximizing Patient Engagement Through Effective Communication • https://dl.dropboxusercontent.com/u/83255422/Blueprint/Maximizing Patient Engagement.mp4 • https://dl.dropboxusercontent.com/u/83255422/Blueprint/Maximizing Patient Engagement.mp4 	Researcher	Inform and higher	Communication
From Partners in Care to Partners in Research (W)	Planetree	<p>Webinar access requires membership.</p> <p>This webinar will share a model of patient and family engagement in research from the Patient-Centered Outcomes Research Institute (PCORI) that will illustrate concrete examples of how patients, caregivers, and patient/caregiver</p>	Both	Involve and higher	Communication, Team function

		<p>organizations are becoming partners in research as part of the design team from determining the research questions to sharing research findings with their communities.</p> <p>The webinar will illustrate the dynamic interplay between patient-centred care and patient-centred research.</p>			
Toolkit on Patient Partner Engagement Research (TOPPER) (M)	HipxChange	<p>Three-hour orientation program that focus on building skills in patient partners with the objective of:</p> <ul style="list-style-type: none"> • Discussing their role as advisors on the research project. • Recognizing common research terms and processes. • Communicating respectfully. • Contributing to effective teamwork. • Providing constructive feedback on research plans and materials. <p>Researchers, clinicians, and public health practitioners can use the toolkit as a template for developing orientation programs for various groups of stakeholders.</p> <p>The orientation materials can be used without revision or adapted for a wide range of patient, caregiver, or community partners.</p> <p>Users of the toolkit can contact WINRS for help adapting the orientation materials.</p> <ul style="list-style-type: none"> • http://winrs.son.wisc.edu/http://winrs.son.wisc.edu/ • http://winrs.son.wisc.edu/ 	Patient	Consult and higher	Communication, Team function, Interpersonal

The Engaging Researcher (C)	Vitae	A highly interactive one-day programme for all researchers who are new to public engagement or those who already have some experience to better understand and plan effective public engagement through a variety of media. Must be a member of Vitae to access education course.	Researcher	Inform and higher	Communication, Interpersonal
Collaborative Researcher (C)	Vitae	A two-day residential programme establishes the building blocks of the collaborative style of research. Whether collaboration is with another academic or partners from different subjects, sectors, and countries, this programme enables researchers at any stage to develop winning strategies for connecting and working with others. Must be member of Vitae and for professional development.	Researcher	Collaborate/ Partner and higher	Communication, Team function, Leadership
Various Continuous Professional Development Training (C)	National Co-ordinating Centre for Public Engagement (NCCPE)	There is a fee to these courses or consultation. Beginners' guide to public engagement This interactive workshop offers delegates the opportunity to explore the key ingredients needed to develop a high-quality public engagement activity. Bespoke training A range of training that can be tailored to your particular needs Example topics include: <ul style="list-style-type: none"> • Impact • Engagement • Quality Engagement • Creative Evaluation Methods • Engagement Skills 	Researcher	Inform and higher	Communication, Team function, Interpersonal

Introduction to Patient and Public Involvement in Research (C)	INVOLVE	This is a one-day training course commissioned by the National Institute for Health Research Clinical Research Network Coordinating Centre (NIHR CCC) with the intention of introducing both researchers and members of the public to patient and public involvement (PPI) in research.	Both	Involve and higher	Communication, Interpersonal
Public Engagement Training Course (C)	Biotechnology and Biological Sciences Research Council (BBSRC)	This course aims to inspire and support researchers to carry out effective public engagement that reflects upon the social and ethical perspectives of their work. By taking part, participants will develop an understanding of what public engagement is, why it is important, the skills required, the broader context of their work, and a deeper empathy with public values, views, concerns, and aspirations. In addition, participants will develop an awareness of the social and ethical issues that might be raised in the context of their research and how to engage with the public in relation to those issues.	Researcher	Inform and higher	Communication, Interpersonal

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Appendix – Resources

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NOTES from Feedback

Much of feedback has been incorporated. The following are notes to consider...

- Document sterile - no "our" or "us" or sense of "belonging to a community of practice" or ? writing as z champion of PE..
Reading whole document may help
- May need safeguards at Levels 4 & 5 in case Pt condition changes
- Questions focus on researcher - rather than research team...
- Suggestion to use this to evaluate current and planned training opportunities for engaging in research
- Apply it to PaCER/ CDRIN
- What level of training can be achieved from the national curriculum?
- Are the range of PE options being met by the range of training options or are their gaps?
- Look at the competencies in light of current and planned initiatives to be sure advice given wrt content/revisions is practical & relevant to real world.

DRAFT 5