0:0:0.0 --> 0:0:4.570
Januwalla, Alia [FH]
Hello and welcome to an introduction to patient oriented research.

0:0:4.640 --> 0:0:10.630
Januwalla, Alia [FH]
This is part of the Dirs Education Workshop series, and it is a prerecorded workshop.

0:0:10.780 --> 0:0:12.470
Januwalla, Alia [FH]
My name is Alia janala.

0:0:12.520 --> 0:0:23.700
Januwalla, Alia [FH]
I'm a knowledge translation specialist with the BC support unit Fraser Center, which is a team in associated with the Department of Evaluation and Research Services at Fraser Health.

0:0:26.620 --> 0:0:42.590
Januwalla, Alia [FH]
I'd like to start to day by acknowledging that Fraser Centre and Fraser Health provide services on the traditional ancestral and unseeded territories of the Coast Salish and in cloud comma nations, and is home to six Metis chartered Communities.

0:0:45.570 --> 0:0:55.90
Januwalla, Alia [FH]
Today's pre recording workshop will introduce the strategy for patient oriented research and the BC support unit our team.

0:0:56.520 --> 0:1:1.660
Januwalla, Alia [FH]
It will also introduce patient oriented research, also known by its acronym poor.

0:1:3.720 --> 0:1:7.910
Januwalla, Alia [FH]
We'll unpack some poor and community based principle.

0:1:7.980 --> 0:1:13.80
Januwalla, Alia [FH]
Of core principles or sorry community based participatory research core principles.

0:1:14.0 --> 0:1:31.840
Januwalla, Alia [FH]
We'll discuss what is patient engagement and also dive into some examples around how Fraser Centre sports Sport and how you might wanna access some of our services to further a conversation or discussion around how patient partners might be able to advance some of the work that you're doing at Fraser Health.

0:1:35.350 --> 0:2:0.680
Januwalla, Alia [FH]
The learning objectives for today are to acquire foundational knowledge about poor and articulate why it is so beneficial to involve patients in health research to describe the various levels of engagement that patient partners can be involved with, and to identify available tools and resources that will conduct that will support the conduct of patient oriented research.

0:2:4.670 --> 0:2:25.220
Januwalla, Alia [FH]
So to to set the stage a little bit around what we're talking about, this is the health research to practice continuum figure and it sort of describes, you know, the the problem behind what the strategy for patient oriented research is trying to fix.

0:2:26.40 --> 0:2:41.310
Januwalla, Alia [FH]
So with health research specifically, it does exist in a slightly different context than other types of research, no matter what kind of research you're doing, there's always a risk that the evidence generated through that research is not making its way to real world impact.

0:2:42.360 --> 0:2:46.950
Januwalla, Alia [FH]
But health research specifically does prevent or present different obstacles.

0:2:48.570 --> 0:3:4.760
Januwalla, Alia [FH]
Health care is often a slow to change field policy change around health care can be really bureaucratic, and practitioners and decision makers and administrators are not likely to take chances on new advancements.

0:3:4.880 --> 0:3:17.710
Januwalla, Alia [FH]
Until that body of evidence for a new approach is really rock solid and that can take years or even decades, there are lives on the line and money is obviously not easily reallocated in the healthcare world.

0:3:19.510 --> 0:3:41.860
Januwalla, Alia [FH]
However, the valley of death metaphor is equally appropriate to describe these two major gaps that we often see in that health research to practice translational research continuum, the first really being that the the translation of laboratory discoveries to human subjects has its own sets of challenges, right?

0:3:41.870 --> 0:3:48.590
Januwalla, Alia [FH]
It's really difficult to go from testing in the lab to test to testing on people, and so there's a valley of death there.

0:3:49.880 --> 0:3:58.780
Januwalla, Alia [FH]
There's a second valley of death when it comes to translating that resulting evidence to clinical and public health practice and policy.

0:4:0.30 --> 0:4:10.300
Januwalla, Alia [FH]
So the gaps between what we actually get between the research of testing on people, to the changes in the system and when it comes to health, decision making and clinical practice.

0:4:12.840 --> 0:4:15.470
Januwalla, Alia [FH]
And this sounds real world impacts, right?

0:4:15.480 --> 0:4:24.730
Januwalla, Alia [FH]
So this can lead to what the research has shown us that 30 to 45% of patients are not receiving care based on scientific evidence.

0:4:25.840 --> 0:4:46.860
Januwalla, Alia [FH]
Whether it's because it's not the most emerging evidence or whether because it's wrong evidence because it's not critically appraised because the right evidence isn't necessarily being indexed, or because what's being indexed isn't necessarily a holistic picture, or because the right partners aren't at the table to also offer different perspectives.

0:4:48.640 --> 0:5:9.110
Januwalla, Alia [FH]
And so this leads us to Canada's strategy for the patient oriented research CIHR, which is Canada's international health research funder really saw these issues in the in in the losses of research and the failures of research that they are not necessarily failures.

0:5:9.120 --> 0:5:30.610
Januwalla, Alia [FH]
But in the gaps in terms of the research that they are funding and the amount of impact that that research was actually generating in the healthcare system and so they created the strategy for patient oriented research and this is Canada's strategy to ensure that the right patient receives the right intervention at the right time.

0:5:31.760 --> 0:5:45.850
Januwalla, Alia [FH]
By increasing the amount of research that's being conducted with and by research, knowledge, users, and when we mean research knowledge users, we mean people who are gonna be able to use those results in that evidence.

0:5:46.360 --> 0:5:49.260
Januwalla, Alia [FH]
And that might mean patients and caregivers for their own health.

0:5:50.770 --> 0:5:55.0
Januwalla, Alia [FH]
It might mean health care providers for how they're providing care.

0:5:55.290 --> 0:5:59.610
Januwalla, Alia [FH]
It might mean health care administrators for the types of programs they're developing.

0:6:0.540 --> 0:6:4.530
Januwalla, Alia [FH]
It might mean decision makers for the types of policies that they're also supporting.

0:6:10.0 --> 0:6:20.270
Januwalla, Alia [FH]
Another sort of I guess thing I wanna wanna bring up is, is our team really looks at health and and health research very broadly.

0:6:20.600 --> 0:6:33.910
Januwalla, Alia [FH]
So sport might have emerged as a response to biomedical and clinical health research, but a lot of our and our teams look at at really broad senses of of, of health.

0:6:33.920 --> 0:6:37.610
Januwalla, Alia [FH]
And so we're looking at things like preventing falls and elderly populations.

0:6:37.980 --> 0:6:39.730
Januwalla, Alia [FH]
Wearable biotechnology.

0:6:40.500 --> 0:6:48.70
Januwalla, Alia [FH]
Walking neighborhoods, anxiety toolkits, quality of life measurements, dietary needs, priority setting and so on.

0:6:48.80 --> 0:6:54.240
Januwalla, Alia [FH]
And so we use a really broad definition of health to justify the use of patient oriented research approaches.

0:6:57.100 --> 0:7:5.930
Januwalla, Alia [FH]
So I'm going to pivot here and talk a little bit about the support units and what they are support stands for support for people in patient oriented research and trials.

0:7:5.940 --> 0:7:11.390
Januwalla, Alia [FH]
And these units are provincial elements of Canada's national strategy for patient oriented research.

0:7:12.520 --> 0:7:17.640
Januwalla, Alia [FH]
BC support unit is one of 10 spore funded support units across Canada.

0:7:19.330 --> 0:7:25.600
Januwalla, Alia [FH]
There are five support BC support unit regional centers that operate in BC.

0:7:26.90 --> 0:7:32.740
Januwalla, Alia [FH]
We are the BC support unit Fraser Center, and we support patient oriented research in the Fraser Salish region.

0:7:33.430 --> 0:7:50.460
Januwalla, Alia [FH]
And so that means that we're a partnership between Fraser Health and Simon Fraser University, but we also work with other academic institutes in the area and and what this means is that there's an institutionalization of poor at both of these institutes.

0:7:50.630 --> 0:8:1.70
Januwalla, Alia [FH]
It means a dedicated allocation of resources to poor leadership, support for poor and, most importantly, fostering important networks between academia and decision makers.

0:8:2.440 --> 0:8:10.690
Januwalla, Alia [FH]
So currently as I record this presentation are BC support unit Fraser Centre team is composed of three staff members.

0:8:11.320 --> 0:8:25.640
Januwalla, Alia [FH]
One of our staff members is a Simon Fraser University employee and the other two of us are Fraser Health staff members and we are within the Department of Evaluation and Research Services at SFU Central City.

0:8:30.710 --> 0:8:52.840
Januwalla, Alia [FH]
And so the BC support unit aims to bridge the gap between research evidence and healthcare practice by providing patient oriented research support services, by strengthening and maintaining BC's capacity in patient oriented research, and by engaging stakeholders as active partners in both research and its use in healthcare practice and policy.

0:8:52.910 --> 0:9:1.700
Januwalla, Alia [FH]
See as I record this presentation, the BC support unit is in year 7 of 10 of our of our phases.

0:9:1.710 --> 0:9:17.0
Januwalla, Alia [FH]
We're we're currently in the second phase and our first phase was really aimed at supporting that capacity in patient oriented research and trying to spread the message about patient oriented research and trying to support teams as much as they could to adopt that approach.

0:9:17.540 --> 0:9:20.20
Januwalla, Alia [FH]
And that's a lot of what we still do today.

0:9:20.30 --> 0:9:38.830
Januwalla, Alia [FH]
And so some of our supports to to to you all at Fraser Health could be things like a patient engagement plans, knowledge translation plans and working with patient partners to be involved in research and evaluation activities generally.

0:9:42.860 --> 0:9:52.110
Januwalla, Alia [FH]
So at this point, we're going to pivot a little bit and talk about patient engagement as sort of an introduction to what we mean by patient oriented research.

0:9:53.970 --> 0:10:9.550
Januwalla, Alia [FH]
I'm when we when we talk about poor, it's really a model that's building on a patient engagement movement that's been ongoing for decades and you know, I think really this movement has really found its feet in the 70s and 80s.

0:10:10.100 --> 0:10:16.330
Januwalla, Alia [FH]
And overall, it's a social movement that has been building momentum at a rapid pace over the last few decades.

0:10:17.180 --> 0:10:22.750
Januwalla, Alia [FH]
It's a concept that's well described by the phrase nothing about me without me.

0:10:25.420 --> 0:10:25.740
Januwalla, Alia [FH]
And.

0:10:28.50 --> 0:10:42.920
Januwalla, Alia [FH]
And this really emerged because patients were noting that shared decision making really does have the potential to improve health outcomes, improve patient and provider satisfactions and save costs.

0:10:44.810 --> 0:11:4.110
Januwalla, Alia [FH]
This perception emerged because, you know, we we were making great strides in scientific discoveries that were indeed improving health outcomes, but yet patient satisfaction was really low due to pay due to poor experiences and at the same time, health care costs were burgeoning.

0:11:4.540 --> 0:11:25.230
Januwalla, Alia [FH]
And so I was a responsive to this came the idea that patients really were partners in their own care, could make those informed, shared decisions, could act as advisors in health system quality improvement and could also be partners in health research.

0:11:27.570 --> 0:11:37.490
Januwalla, Alia [FH]
And so patient engagement in health research is also building on a history of community based participatory research at its core, community based research is collaborative.

0:11:37.780 --> 0:11:47.200
Januwalla, Alia [FH]
Concerned with equity involves community and university scholars as equal partners, and combines knowledge with action, usually to achieve social change.

0:11:48.430 --> 0:11:53.40
Januwalla, Alia [FH]
And there's a wide school of thought behind both of these disciplines.

0:11:53.50 --> 0:11:55.480
Januwalla, Alia [FH]
I've linked to one resource here as well.

0:11:56.240 --> 0:12:2.890
Januwalla, Alia [FH]
Patient oriented research specifically, which I'll define in the in the next slide, really does borrow on a lot of these principles.

0:12:3.930 --> 0:12:8.140
Januwalla, Alia [FH]
The focus of poor is just around realigning that.

0:12:8.190 --> 0:12:12.440
Januwalla, Alia [FH]
A typical model of research, specifically in the health field.

0:12:16.890 --> 0:12:19.50
Januwalla, Alia [FH]
I am, and so poor.

0:12:19.60 --> 0:12:21.810
Januwalla, Alia [FH]
Uh, when we when we define poor this.

0:12:21.820 --> 0:12:40.500
Januwalla, Alia [FH]
This is sort of how we're defining it, and one quick note is that patient oriented research or poor is Canada's approach, but there are similar initiatives in the UK and the US All three initiatives have slightly different approaches, but they all have roots in community based research and branched out from there.

0:12:42.640 --> 0:12:51.990
Januwalla, Alia [FH]
And so when we talk about poor or defining as poor is that it engages patients as partners in research and not as participants.

0:12:52.640 --> 0:12:57.390
Januwalla, Alia [FH]
So this is very different from engaging part patients as study participants.

0:12:57.980 --> 0:13:1.570
Januwalla, Alia [FH]
We're not engaging patients to draw data from them.

0:13:2.300 --> 0:13:14.110
Januwalla, Alia [FH]
We're actually engaging them to support us in the decision making of research practices and so partners patient partners are considered equal members of the research team.

0:13:16.410 --> 0:13:27.410
Januwalla, Alia [FH]
Patient oriented research also focuses on priorities that have been identified by patients to improve outcomes that have also been defined by patients.

0:13:29.630 --> 0:13:40.210
Januwalla, Alia [FH]
It aims to apply knowledge that's generated to improve healthcare systems and practices, and has also conducted by multidisciplinary teams in partnership with stakeholders.

0:13:41.140 --> 0:13:46.630
Januwalla, Alia [FH]
And what we mean by multidisciplinary teams is that we really have a diverse set of knowledge.

0:13:46.640 --> 0:14:4.620
Januwalla, Alia [FH]
Users at the table clinicians, other Allied health care professionals or professionals, other healthcare providers, academic researchers, decision makers, administrators, evaluators and, of course, patient partners, caregivers, family members, etc.

0:14:8.80 --> 0:14:17.560
Januwalla, Alia [FH]
And so again, what we mean is that research is done with and by patients and not for on or about.

0:14:20.230 --> 0:14:25.820
Januwalla, Alia [FH]
A quick note here about terminology is that patient isn't always the right word.

0:14:26.210 --> 0:14:42.700
Januwalla, Alia [FH]
When we say patient, we're defining it as any person that has experienced a healthcare issue or the healthcare system, including informal caregivers, family, friends, umm, we recognize that, you know, patient isn't always that right term, it turns some people off.

0:14:42.780 --> 0:14:57.570
Januwalla, Alia [FH]
And in fact, there are a lot of people who prefer to be called clients, residents, public members, community members, and I think what's important here is to recognize that lived experience is the most critical.

0:14:57.580 --> 0:15:0.160
Januwalla, Alia [FH]
And so it's always important just to ask them.

0:15:0.220 --> 0:15:5.250
Januwalla, Alia [FH]
Ask your partners how they would like to be identified or defined, and then they're amend your language accordingly.

0:15:8.20 --> 0:15:18.750
Januwalla, Alia [FH]
And so again, what we're doing here is shifting our our our thinking about shifting our traditional perceptions of the research model and whose generating and receiving or using knowledge.

0:15:19.840 --> 0:15:28.780
Januwalla, Alia [FH]
So this slide shows that traditional model of academic researchers generating knowledge and passing it on to others as knowledge users.

0:15:30.910 --> 0:15:38.340
Januwalla, Alia [FH]
What we're trying to do is flip this model on its head and Createspace for all of these types of roles.

0:15:38.490 --> 0:15:47.960
Januwalla, Alia [FH]
To be knowledge, producers and users exchanging experience, learning together and leveraging each other's expertise to generate higher quality evidence.

0:15:49.640 --> 0:15:59.260
Januwalla, Alia [FH]
This engagement can occur anywhere in the research cycle, from research, question generation, and grant writing all the way to data analysis and dissemination.

0:15:59.270 --> 0:16:9.300
Januwalla, Alia [FH]
And we'll talk a little bit more about some of those examples in terms of where in the research cycle, this sort of collaboration can occur, which is everywhere.

0:16:13.280 --> 0:16:17.510
Januwalla, Alia [FH]
So again, this is an example of different terminology that might be used.

0:16:18.240 --> 0:16:29.110
Januwalla, Alia [FH]
It's not always patient, might not always be appropriate, but we're really talking about an individuals with lived experience of a health issue that's relevant to that focus of that research.

0:16:32.650 --> 0:16:33.0
Januwalla, Alia [FH]
Umm.

0:16:36.440 --> 0:16:38.110
Januwalla, Alia [FH]
And so with patience.

0:16:38.860 --> 0:16:39.390
Januwalla, Alia [FH]
Patience.

0:16:39.450 --> 0:16:40.90
Januwalla, Alia [FH]
Really.

0:16:40.100 --> 0:16:40.330
Januwalla, Alia [FH]
What?

0:16:40.340 --> 0:16:45.670
Januwalla, Alia [FH]
What matters to them, of course, is being heard being seen.

0:16:47.310 --> 0:16:57.580
Januwalla, Alia [FH]
What they're really after, when they're engaging in these sorts of activities is those real improvements to the healthcare system for those that come after them and better health outcomes and experiences.

0:16:59.70 --> 0:17:12.180
Januwalla, Alia [FH]
And so really making sure that we're following through on the research and that we're involving patients with that KT piece is just as important because that's really the reason why they're getting involved with this research.

0:17:15.0 --> 0:17:16.930
Januwalla, Alia [FH]
So why do we engage patients?

0:17:17.30 --> 0:17:19.210
Januwalla, Alia [FH]
And this is a really great figure.

0:17:19.220 --> 0:17:30.880
Januwalla, Alia [FH]
I love this figure because it really shows I think the difference between what happens when you design something without really taking user experience into account.

0:17:32.10 --> 0:17:38.480
Januwalla, Alia [FH]
And this is an image that shows, you know, the architects, probably at a paved path.

0:17:38.950 --> 0:17:59.420
Januwalla, Alia [FH]
And yet there is a path that is more trodden because it is shorter and it gets from .8 point B quicker, and it tends to be the path that most people are taking anyway, and so it's important to consider the patient perspective before you actually implement a program design or research question.

0:17:59.430 --> 0:18:1.710
Januwalla, Alia [FH]
A research study umm.

0:18:2.150 --> 0:18:3.390
Januwalla, Alia [FH]
And those sorts of things.

0:18:6.180 --> 0:18:10.190
Januwalla, Alia [FH]
There's a lot of other benefits, of course, that patient engagement in health research.

0:18:10.690 --> 0:18:13.600
Januwalla, Alia [FH]
I'm just to reiterate some of these.

0:18:13.950 --> 0:18:19.660
Januwalla, Alia [FH]
It improves the relevance of the research and makes it more likely to actually have an impact on patients.

0:18:20.810 --> 0:18:21.850
Januwalla, Alia [FH]
It improves the quality.

0:18:23.530 --> 0:18:26.850
Januwalla, Alia [FH]
There's a greater impact on the lives of patients and the health care system.

0:18:27.730 --> 0:18:37.50
Januwalla, Alia [FH]
It leads to more ethical research, fosters inclusive mechanisms and processes, facilitates multiway capacity buildings.

0:18:37.60 --> 0:18:44.840
Januwalla, Alia [FH]
So there's a lot of opportunities for many members of the research team to learn to learn how to communicate and collaborate.

0:18:47.130 --> 0:18:58.770
Januwalla, Alia [FH]
It emphasizes that experiential knowledge and knowledge that we're actually at, you know, based on our lived experience, that's valued as evidence, as mobilized and translated for impact.

0:18:58.830 --> 0:19:3.420
Januwalla, Alia [FH]
And and there's a shared sense of purpose.

0:19:3.480 --> 0:19:9.250
Januwalla, Alia [FH]
And I think most importantly, it's that moral imperative around nothing about us without us.

0:19:12.630 --> 0:19:19.120
Januwalla, Alia [FH]
There's a number of studies and scoping reviews that have been done to illustrate the benefits of patient engagement in health research.

0:19:19.170 --> 0:19:31.580
Januwalla, Alia [FH]
And so ioffer some of this literature here just to highlight some of those benefits and at that the do and you know exist and has sort of how that impact that it does have in the healthcare system.

0:19:36.730 --> 0:20:8.340
Januwalla, Alia [FH]
So when we talk about patient engagement, we're really talking about these and at guiding principles and so patient engagement, what we were working under that is to find as the meaningful and active collaboration and governance priority priority setting, conducting research and or knowledge translation and it's guided by these principles of inclusiveness, the port mutual respect and Co building.

0:20:10.370 --> 0:20:27.170
Januwalla, Alia [FH]
And these are some of the quotes here that have been offered by patient partners and those who work with patient partners that really I think well encapsulate and the sort of principles that and and impact of patient engagement is awful.

0:20:36.580 --> 0:20:49.230
Januwalla, Alia [FH]
Umm, I really like this figure because I I think it kind of well well demonstrates the domino effect from what it means to engage with knowledge users and what we mean knowledge users.

0:20:49.240 --> 0:20:58.600
Januwalla, Alia [FH]
Again, we're talking about patient partners, healthcare providers, program staff, administrators, caregivers and researchers.

0:20:58.910 --> 0:21:10.700
Januwalla, Alia [FH]
But when we identify with all of those knowledge users and they undertake research, there tends to be a multi way and collaboration in terms of that research.

0:21:12.850 --> 0:21:16.590
Januwalla, Alia [FH]
Research tends to be conducted in areas that the knowledge users also value.

0:21:18.410 --> 0:21:30.390
Januwalla, Alia [FH]
These knowledge users then influence and accelerate decision making, translation and uptake of new practices, and this results in improved experience and propelled outcomes and more sustainable health care system.

0:21:30.960 --> 0:21:45.10
Januwalla, Alia [FH]
And so I really offered this to drive home the point that there is value in engaging with a wide variety of knowledge users, particularly patient partners, in order to really see an impact and a change in the healthcare system.

0:21:46.180 --> 0:21:51.140
Januwalla, Alia [FH]
We're not going to make a change if we just keep asking ourselves the same questions.

0:21:51.560 --> 0:21:59.490
Januwalla, Alia [FH]
And so it's important to to gather all those different perspectives when we're thinking about making a change in uptake of new practices.

0:22:3.850 --> 0:22:28.850
Januwalla, Alia [FH]
This is a really great example in terms of the importance of engaging with patients with lived experience and and this example is around spinal cord injury research, so a lot of the majority of research prior to the early 2000s around spinal cord injury focused on getting people back to walking.

0:22:30.50 --> 0:22:41.380
Januwalla, Alia [FH]
There's millions of dollars going in his final cord injury and the majority of it was just focused on outcomes that a researcher who themselves had a spinal cord injury knew wasn't.

0:22:41.630 --> 0:22:52.880
Januwalla, Alia [FH]
Anecdotally, the main priority, so because they had their own lived experience to sort of knew, OK, I don't know why so much of this research is focused on walking when it's not necessarily a patient identified outcome.

0:22:53.630 --> 0:22:55.460
Januwalla, Alia [FH]
And so they surveyed this.

0:22:55.470 --> 0:23:2.600
Januwalla, Alia [FH]
Researchers surveyed 700 people with spinal cord injury and actually found a whole number of different priorities.

0:23:3.270 --> 0:23:21.140
Januwalla, Alia [FH]
They found that those with spinal cord injury are actually much more concerned with things that affect their daily quality of life, their bowel care, their sexual function, their hand function and very little research was actually being done to support these priorities.

0:23:22.850 --> 0:23:47.750
Januwalla, Alia [FH]
And so this priority setting work led to a huge research program and many knowledge translation products for patients and providers that really improved care and quality of life for people living with spinal cord injury that would not have been done had lived experience, not been a key component of that story and had patience not been engaged to identify research priorities.

0:23:54.120 --> 0:24:3.270
Januwalla, Alia [FH]
So the next few sections or next few slides are going to talk about some details around patient engagement and how to develop it and a patient engagement plan.

0:24:6.240 --> 0:24:9.870
Januwalla, Alia [FH]
This no matter the field that you want to work in or the size of the project.

0:24:9.880 --> 0:24:15.830
Januwalla, Alia [FH]
If you want to start engaging with a patient partner, you wanna start with creating an engagement plan.

0:24:16.680 --> 0:24:20.500
Januwalla, Alia [FH]
There needs to be a plan in place before you start so you can start with intention.

0:24:21.910 --> 0:24:30.580
Januwalla, Alia [FH]
If you don't have the right people on board, you might not succeed in finding your population getting the data you need, implementing your findings, or making an impact.

0:24:31.830 --> 0:24:44.230
Januwalla, Alia [FH]
We need to plan for engagement of all knowledge users, not just the public impatience and your plans might be different for different knowledges, your groups, but your plan is typically going to ask the following questions.

0:24:45.800 --> 0:24:49.670
Januwalla, Alia [FH]
You might want to ask who have you engaged with or plan to engage with?

0:24:50.960 --> 0:24:52.510
Januwalla, Alia [FH]
Why those people?

0:24:52.520 --> 0:24:56.840
Januwalla, Alia [FH]
So, umm, why are you targeting these knowledge users?

0:24:58.700 --> 0:25:5.130
Januwalla, Alia [FH]
What will they contribute to the project once they're engaged, and how will you initiate an engagement with them?

0:25:8.10 --> 0:25:11.280
Januwalla, Alia [FH]
And we're going to unpack some of these questions a little bit more specifically.

0:25:12.600 --> 0:25:14.760
Januwalla, Alia [FH]
So let's talk about the first question.

0:25:14.770 --> 0:25:16.360
Januwalla, Alia [FH]
Who do I need to engage with?

0:25:18.260 --> 0:25:25.380
Januwalla, Alia [FH]
We really want to ask who is the research about who might find your research relevant in their life or in their work?

0:25:28.0 --> 0:25:32.200
Januwalla, Alia [FH]
Will anyone be personally impacted by your methods or findings?

0:25:33.670 --> 0:25:41.100
Januwalla, Alia [FH]
So for example, if your research is about I'm dietary needs or dietary needs for.

0:25:43.280 --> 0:25:57.120
Januwalla, Alia [FH]
People with type 2 diabetes, you might want to engage patients and caregivers, patients who have type 2 diabetes and caregivers who support those patients to better inform some of your dietary needs.

0:25:57.130 --> 0:26:1.630
Januwalla, Alia [FH]
Research you might want to you might wanna engage with that.

0:26:1.800 --> 0:26:5.730
Januwalla, Alia [FH]
Dietitians you might wanna engage with other healthcare providers as necessary.

0:26:5.740 --> 0:26:11.840
Januwalla, Alia [FH]
Depending on that research, but you wanna think through, will anyone be personally impacted by my methods or my findings?

0:26:14.590 --> 0:26:25.450
Januwalla, Alia [FH]
You also need to ask who do you need on boards to make the sure the research happens, so you might want to ask yourself do you need approval from any department heads or management?

0:26:26.230 --> 0:26:31.170
Januwalla, Alia [FH]
Do you need involvement from certain stock groups to help with recruitment or consenting?

0:26:34.10 --> 0:26:37.800
Januwalla, Alia [FH]
Do you need financial or in kind support from anyone?

0:26:39.510 --> 0:26:42.260
Januwalla, Alia [FH]
Do you need access to people or data?

0:26:44.750 --> 0:26:45.60
Januwalla, Alia [FH]
And.

0:26:49.450 --> 0:26:54.410
Januwalla, Alia [FH]
And are your patient project partners represented of your population?

0:26:57.30 --> 0:26:57.990
Januwalla, Alia [FH]
Is anyone missing?

0:26:59.490 --> 0:27:11.670
Januwalla, Alia [FH]
And of course, we understand that we can't always include all voices and perspectives in every project, but we need to keep equity, diversity, inclusion and access at the front of our minds when we consider who needs to be engaged.

0:27:13.50 --> 0:27:17.50
Januwalla, Alia [FH]
And so you really do need to ask the questions around who is your population?

0:27:18.90 --> 0:27:20.590
Januwalla, Alia [FH]
Are your patient partners representative of that population?

0:27:21.920 --> 0:27:25.80
Januwalla, Alia [FH]
Are there any underrepresented voices that haven't been considered?

0:27:26.660 --> 0:27:30.960
Januwalla, Alia [FH]
Have you created an environment or an opportunity for those voices to come forward?

0:27:32.440 --> 0:27:37.680
Januwalla, Alia [FH]
And as a note, it's always best practice to have more than one patient involved as a project partner.

0:27:41.610 --> 0:27:48.640
Januwalla, Alia [FH]
The the next question that kind of comes to the the engagement plan is around why are you engaging with those people?

0:27:48.730 --> 0:27:56.600
Januwalla, Alia [FH]
And this is really meant to help you hone in on your engagement plan and focus it, but also to help you avoid engaging people in a tokenistic way.

0:27:58.10 --> 0:28:2.510
Januwalla, Alia [FH]
You need to have a really genuine and good reason for engaging.

0:28:4.790 --> 0:28:9.860
Januwalla, Alia [FH]
So you might wanna ask, you know, are you answering a question that matters to knowledge users?

0:28:11.730 --> 0:28:12.930
Januwalla, Alia [FH]
Are you using language?

0:28:12.940 --> 0:28:14.610
Januwalla, Alia [FH]
That's appropriate for your population.

0:28:17.490 --> 0:28:31.480
Januwalla, Alia [FH]
Those are all sorts of considerations where engaging with patient partners might contribute, often grant applications and administrative approvals, and may require some level of engagement as well.

0:28:31.490 --> 0:28:35.350
Januwalla, Alia [FH]
So often uh, we're seeing a lot more grants require a patient engagement plan.

0:28:38.400 --> 0:28:39.410
Januwalla, Alia [FH]
I'm patient.

0:28:39.420 --> 0:28:43.50
Januwalla, Alia [FH]
Partners can also, you know, offer feedback on feasibility.

0:28:43.60 --> 0:28:44.440
Januwalla, Alia [FH]
Scope timelines.

0:28:46.680 --> 0:28:50.610
Januwalla, Alia [FH]
Are you engaging with them because they might be able to help with recruitment?

0:28:52.370 --> 0:28:55.880
Januwalla, Alia [FH]
Is that population appropriate for your research strategy?

0:28:56.390 --> 0:29:2.230
Januwalla, Alia [FH]
And so these are certain reasons why you might be engaging with patient partners as well.

0:29:6.310 --> 0:29:7.700
Januwalla, Alia [FH]
The way to engage.

0:29:7.910 --> 0:29:14.330
Januwalla, Alia [FH]
So how you're gonna engage with them is somewhat dictated by what you're looking for from each person and how they would like to be involved.

0:29:15.420 --> 0:29:16.510
Januwalla, Alia [FH]
Always ask.

0:29:16.820 --> 0:29:23.990
Januwalla, Alia [FH]
Don't assume a common misconception is that people don't want to be bothered and want to be involved as little as possible.

0:29:24.0 --> 0:29:26.40
Januwalla, Alia [FH]
That that's not necessarily the case.

0:29:26.360 --> 0:29:30.500
Januwalla, Alia [FH]
So just ask people what they have the capacity for or they're interested in.

0:29:32.10 --> 0:29:38.180
Januwalla, Alia [FH]
It's also helpful to consider this scale of engagement levels from the International Association for Public Participation.

0:29:38.770 --> 0:29:46.440
Januwalla, Alia [FH]
The scale goes from inform, which is the lowest level of engagement to empower, which is the highest level of engagement.

0:29:48.220 --> 0:29:51.450
Januwalla, Alia [FH]
None of these categories are better or worse than the other.

0:29:51.460 --> 0:29:54.620
Januwalla, Alia [FH]
And they can all be useful in different contexts.

0:30:1.460 --> 0:30:3.210
Januwalla, Alia [FH]
And what will your partners contribute?

0:30:4.840 --> 0:30:9.90
Januwalla, Alia [FH]
You always want to describe the whole project and ask what interests them.

0:30:10.840 --> 0:30:18.80
Januwalla, Alia [FH]
People bring rich experiences and skill sets to projects and are more than just their lived experience of a certain topic or issue.

0:30:19.350 --> 0:30:24.20
Januwalla, Alia [FH]
And so asking them how they would like to contribute builds trust and makes the work better.

0:30:25.580 --> 0:30:53.890
Januwalla, Alia [FH]
Applicants or not, a sorry project partners, patient partners might have skills that they want to engage in and that they want to contribute to this, such as scientific communication, writing, editing, reading, presentation, skills, analysis, other might be a whole range of skills that they're really interested in and asking them what they want to contribute is a really good way of facilitating that kind of that conversation.

0:30:55.230 --> 0:31:5.430
Januwalla, Alia [FH]
Umm, it's also good practice to sort of note that in in terms of reference or some sort of guiding document and to sort of set expectations for what that involvement can look like.

0:31:12.90 --> 0:31:15.170
Januwalla, Alia [FH]
And so again, we sort of talked about this spectrum.

0:31:15.180 --> 0:31:29.390
Januwalla, Alia [FH]
Again, I'll just skip it because I think we've talked about a lot of this content, but this is a another slide that sort of offers a few example strategies that fit under some of these methods of engagement.

0:31:29.660 --> 0:31:53.560
Januwalla, Alia [FH]
So if you were to inform a population, it might be something like handing out a newsletter, a website, maybe, a kiosk, things like that involving collaborating and empowering are usually when you might be engaging in in forms of decision making that have that that have slightly more of an increasing impact.

0:31:53.810 --> 0:32:0.840
Januwalla, Alia [FH]
And so these forms might look like things like an advisory group or working group, A steering committee, a Governing Council.

0:32:2.340 --> 0:32:10.570
Januwalla, Alia [FH]
Poor models tend to fit in the involved to empower end of the spectrum, but again this is not a one.

0:32:10.580 --> 0:32:20.360
Januwalla, Alia [FH]
All and be all, and they can also extend to involve and consult depending on how the patient partners would like to be involved in engaged.

0:32:21.890 --> 0:32:36.500
Januwalla, Alia [FH]
And so it's really up to you to ask, you know, some patient partners would like to just receive updates and provide their up to provide their input whenever they'd like in whatever capacity they want to you others wanna be more engaged in every step of the decision making.

0:32:36.690 --> 0:32:40.950
Januwalla, Alia [FH]
And so that's a conversation you can have with your patient partner and the rest of your research team.

0:32:45.690 --> 0:32:55.200
Januwalla, Alia [FH]
Umm, but this diagram shows the research cycle and we typically use it to illustrate places where patient partners can contribute to projects, which is everywhere.

0:32:55.760 --> 0:33:9.580
Januwalla, Alia [FH]
And so today I wanna highlight there's a lot of other responsibilities that also exist outside of the cycle, project management coordination and communication of project personnel and participants and other vital roles that need to be accounted for.

0:33:10.250 --> 0:33:53.10
Januwalla, Alia [FH]
Those roles that those activities that typically happen in a research study, those are typically activities that a staff person would do and not a patient partner and really important to designate a staff person to do some of those project management and communication and coordination PC pieces to ensure a consistent and smooth project for patient partners can be involved in setting priorities and formulating the study question, identifying your study population, your recruitment strategies, choosing relevant outcomes they might be involved in data analysis and interpreting the findings and the relevancy of those findings.

0:33:54.740 --> 0:34:4.520
Januwalla, Alia [FH]
They can also be involved in designing implementation activities, translating those documents into plain language and other strategies that might be effective for patients and communities.

0:34:6.310 --> 0:34:10.810
Januwalla, Alia [FH]
They might also help develop practice guidelines and inform evaluation practices.

0:34:16.390 --> 0:34:16.800
Januwalla, Alia [FH]
Umm.

0:34:17.60 --> 0:34:24.340
Januwalla, Alia [FH]
And so these are just some other sort of guiding questions when it comes to creating a patient engagement plan.

0:34:25.250 --> 0:34:37.700
Januwalla, Alia [FH]
Other questions to ask yourself as someone who's a research team member, or someone who might be starting to walk that journey in developing a patient engagement plan, how are you meeting people where they're at?

0:34:39.170 --> 0:34:40.640
Januwalla, Alia [FH]
So what's their level of health?

0:34:40.870 --> 0:34:43.290
Januwalla, Alia [FH]
Research, knowledge or health research literacy.

0:34:44.730 --> 0:34:59.870
Januwalla, Alia [FH]
Do you need to provide them with any other reading materials or any other support training orientation learning so that they can feel supported and feel that they're able to show up and be engaged with all the supports that they have?

0:35:1.760 --> 0:35:4.510
Januwalla, Alia [FH]
Do you have a point person on your team for patient partners?

0:35:4.520 --> 0:35:10.210
Januwalla, Alia [FH]
So we do typically say that it's best practice to identify one point person at least.

0:35:10.280 --> 0:35:31.300
Januwalla, Alia [FH]
Who can be that liaison between patient partners and be that person that communicates with the patient, partners that provides updates if a patient partner can't attend meetings and that that provides check-ins to the patient partners that provides an opportunity for the patient partner to voice any concerns they might have?

0:35:31.440 --> 0:35:33.380
Januwalla, Alia [FH]
Or is just generally a safe space?

0:35:35.80 --> 0:35:38.190
Januwalla, Alia [FH]
You might also want to consider what's the preferred method of communication.

0:35:38.200 --> 0:35:40.310
Januwalla, Alia [FH]
So do they like online meetings?

0:35:40.320 --> 0:35:42.310
Januwalla, Alia [FH]
Do they like phone calls?

0:35:42.380 --> 0:35:43.400
Januwalla, Alia [FH]
Or those sorts of things.

0:35:44.730 --> 0:35:50.380
Januwalla, Alia [FH]
What are the roles and responsibilities for all the team members and how often are you checking in with patient partners?

0:35:52.40 --> 0:35:59.780
Januwalla, Alia [FH]
Our team at the BC Support unit does have a patient engagement planning template and we can help walk you through a lot of these questions.

0:35:59.790 --> 0:36:9.790
Januwalla, Alia [FH]
So it's a free service that we offer to everyone up for Azure Health who would like to start and you know adopting a patient oriented research approach into their research.

0:36:10.0 --> 0:36:18.700
Januwalla, Alia [FH]
And so you're welcome to to reach out to our team and we can chat a little bit more about how these questions might look in your context and stay.

0:36:22.550 --> 0:36:23.120
Januwalla, Alia [FH]
You know it.

0:36:23.130 --> 0:36:45.30
Januwalla, Alia [FH]
It is true that doing this work is a shift from the traditional research model and it doesn't come without challenges, and it does require a time and effort and additional resources, and that can be built into grants and timelines.

0:36:45.940 --> 0:36:54.390
Januwalla, Alia [FH]
So there is a, you know, a recognition that engagement does take time and effort, but you can start thinking about how to build that into your grants and timelines.

0:36:54.400 --> 0:37:0.900
Januwalla, Alia [FH]
And of course, working with our team can sort of help navigate how you might budget for some of these pieces.

0:37:3.620 --> 0:37:4.20
Januwalla, Alia [FH]
Umm.

0:37:4.500 --> 0:37:10.330
Januwalla, Alia [FH]
Power dynamics can be another challenge that can come up.

0:37:10.380 --> 0:37:19.190
Januwalla, Alia [FH]
It can be hard for researchers or for people in traditional positions of power to give up control over their work, but it is necessary in this kind of approach.

0:37:21.300 --> 0:37:21.660
Januwalla, Alia [FH]
Umm.

0:37:28.30 --> 0:37:30.810
Januwalla, Alia [FH]
Doing this work can can take resources back to that point.

0:37:30.820 --> 0:37:54.810
Januwalla, Alia [FH]
We do need to make it the norm to build additional time and money into our grants in order to do work like this properly and and so it's important that we do recognize that project patient partners who are volunteering their time to engage in this way and our office staff should be reimbursed for out of pocket expenses and if possible, should be compensated for their time.

0:37:56.90 --> 0:38:0.770
Januwalla, Alia [FH]
We also need to build in flexibility and the ability for timelines to shift.

0:38:2.0 --> 0:38:16.310
Januwalla, Alia [FH]
Oftentimes this work is very iterative because of the amount of knowledge users that are involved, and because of the scope of relationship building that often needs to occur before the work actually gets going.

0:38:16.320 --> 0:38:22.600
Januwalla, Alia [FH]
And so it's important to just build those timelines into your grants and things like that.

0:38:25.780 --> 0:38:35.280
Januwalla, Alia [FH]
Tokenism is also a can be a key challenge when it comes to doing this work, and in order to combat tokenism.

0:38:35.290 --> 0:38:38.150
Januwalla, Alia [FH]
First, you really need to consider why are you engaging.

0:38:40.260 --> 0:38:49.220
Januwalla, Alia [FH]
Patients should be diverse in their experience and representative of the population that you're researching and engagement should be meaningful, genuine, and culturally safe.

0:38:50.570 --> 0:38:58.700
Januwalla, Alia [FH]
Your partners should be included as equal team members, which means thinking about engagement really early on and not bringing people on last minute.

0:39:0.700 --> 0:39:8.120
Januwalla, Alia [FH]
That commitment to mutual learning and collaboration and making it effort to maintain enduring relationships.

0:39:8.180 --> 0:39:25.120
Januwalla, Alia [FH]
So again, it does come back to that piece of I'm forming strong and lasting relationships and taking that time to build trusting relationships between your knowledge users to overcome a lot of these challenges including tokenism and power dynamics.

0:39:30.710 --> 0:39:31.210
Januwalla, Alia [FH]
Umm.

0:39:31.410 --> 0:39:45.800
Januwalla, Alia [FH]
And so having partnership agreements, a terms of reference or something that documents how the term will work together can be a really good strategy in terms of conflict prevention and facilitating smooth teamwork.

0:39:47.890 --> 0:39:54.20
Januwalla, Alia [FH]
These are both strategies that can you know that can be worked through by working with the Fraser Center.

0:39:54.110 --> 0:40:8.100
Januwalla, Alia [FH]
We can help facilitate strategies for conflict prevention and conflict resolution, but some of the strategies that we suggest for conflict prevention are things like terms of reference or partnership agreements.

0:40:8.510 --> 0:40:20.330
Januwalla, Alia [FH]
Creating an environment where everyone is heard and feels heard, open and continuous communication, building and maintaining relationships and team building exercises.

0:40:22.670 --> 0:40:24.0
Januwalla, Alia [FH]
A conflict resolution.

0:40:24.10 --> 0:40:26.520
Januwalla, Alia [FH]
Some strategies we also occur.

0:40:26.750 --> 0:40:40.390
Januwalla, Alia [FH]
We also suggest are engaging with the Fraser Centre to possibly support you in navigating a conflict resolution, but regular check-ins can also help catch things before they bubble up.

0:40:41.800 --> 0:40:43.600
Januwalla, Alia [FH]
Acting early when an issue arises.

0:40:45.550 --> 0:40:55.110
Januwalla, Alia [FH]
Going back to your terms of reference and partnership agreements, finding a neutral third party to adjudicate, and that must mean that might be the furniture center.

0:40:56.330 --> 0:41:7.890
Januwalla, Alia [FH]
Umm, but perhaps maybe also recognizing when it is time to walk away from a partnership, or finding another opportunity for someone to engage.

0:41:7.900 --> 0:41:11.50
Januwalla, Alia [FH]
That might not look the same as outlined.

0:41:12.810 --> 0:41:17.0
Januwalla, Alia [FH]
Again, those are all strategies that can be discussed further with the Fraser Centre.

0:41:17.10 --> 0:41:23.750
Januwalla, Alia [FH]
If the server were to arise but of a lot of what we've discussed already, when it comes to the questions that would be.

0:41:25.930 --> 0:41:33.140
Januwalla, Alia [FH]
Part of your patient engagement plan will go a long way to mitigating and preventing conflict from happening.

0:41:38.630 --> 0:41:52.610
Januwalla, Alia [FH]
I am when it comes to engaging with indigenous people, of course, there's a recognition that historical harms have been caused by colonial research enterprise.

0:41:53.720 --> 0:41:58.440
Januwalla, Alia [FH]
And so when it comes to engaging with indigenous peoples for research, engagement is not optional.

0:42:0.180 --> 0:42:1.390
Januwalla, Alia [FH]
Research generation.

0:42:2.320 --> 0:42:14.960
Januwalla, Alia [FH]
Will come from the community and supported by others as needed, and so the way that we see engagement with additions, peoples and research context is always that that's research led by the Community and we can support.

0:42:15.700 --> 0:42:17.630
Januwalla, Alia [FH]
I'm a as needed.

0:42:18.200 --> 0:42:20.180
Januwalla, Alia [FH]
Fraser Center is working with.

0:42:22.570 --> 0:42:44.140
Januwalla, Alia [FH]
With meeting nations BC, the Indigenous cultural safety team, the BC network environment for Indigenous Health Research and other academic and community partners to develop a protocol for engaging with indigenous peoples in in research and evaluation that will be specific to the Fraser salvage region.

0:42:44.530 --> 0:42:46.30
Januwalla, Alia [FH]
So just keep an eye out for that.

0:42:46.40 --> 0:42:51.990
Januwalla, Alia [FH]
That will be shared in the coming probably coming here years, five years.

0:42:52.240 --> 0:42:52.450
Januwalla, Alia [FH]
Thank you.

0:42:58.520 --> 0:42:58.820
Januwalla, Alia [FH]
Umm.

0:43:1.360 --> 0:43:5.930
Januwalla, Alia [FH]
I'll touch very briefly on this notion of trauma and resiliency.

0:43:5.940 --> 0:43:8.380
Januwalla, Alia [FH]
Informed practice in a research context.

0:43:9.610 --> 0:43:9.910
Januwalla, Alia [FH]
Umm.

0:43:10.860 --> 0:43:20.130
Januwalla, Alia [FH]
Oftentimes, people join research project projects as patient partners because they may have had a negative experience in their own care journey and one would improve things for future patients.

0:43:21.70 --> 0:43:28.70
Januwalla, Alia [FH]
However, at these negative experiences can carry trauma, and by participating, we're asking people to share those traumas.

0:43:30.120 --> 0:43:37.250
Januwalla, Alia [FH]
Often to lots of people, sometimes for free, and so we need to be mindful of asking people what they're comfortable sharing.

0:43:38.220 --> 0:43:38.950
Januwalla, Alia [FH]
Planning ahead.

0:43:38.960 --> 0:43:52.170
Januwalla, Alia [FH]
So we don't put them on the spot and drawing clear lines around what people are comfortable with, the research team sharing in publications as well, and something I've I've learned from my colleague.

0:43:52.180 --> 0:44:3.380
Januwalla, Alia [FH]
But from Roy, who is an expert in this work, is that we need to remember that sharing and vulnerability cannot be a one way St and that is part of relationship building.

0:44:3.390 --> 0:44:8.330
Januwalla, Alia [FH]
We need to be willing to share our own experiences and be compassionate for ourselves.

0:44:8.410 --> 0:44:9.770
Januwalla, Alia [FH]
And those we are working with.

0:44:11.960 --> 0:44:18.380
Januwalla, Alia [FH]
And so ioffer some reading here to dive into trauma and resiliency informed practices, a little bit more.

0:44:19.450 --> 0:44:25.340
Januwalla, Alia [FH]
There is some training available for trauma, informed trauma and trauma and resiliency.

0:44:25.350 --> 0:44:29.140
Januwalla, Alia [FH]
Informed practices for research and evaluation specifically as well.

0:44:33.270 --> 0:44:36.300
Januwalla, Alia [FH]
But to wrap up and engagement does take time.

0:44:36.450 --> 0:44:45.110
Januwalla, Alia [FH]
It I think it's well defined by these three sort of these these three themes collaboration.

0:44:47.670 --> 0:44:54.180
Januwalla, Alia [FH]
There are multiple knowledge users that need to be involved in engagement and patient oriented research.

0:44:55.320 --> 0:45:8.480
Januwalla, Alia [FH]
It's also defined by curiosity, and it's also defined by humility, and I think a a constant key for success when we were walking that poor path is that it's a constant journey of learning.

0:45:11.440 --> 0:45:18.60
Januwalla, Alia [FH]
The next section will just be a few tools and resources that we've linked to for you to dive into a bit further on your poor journey.

0:45:20.370 --> 0:45:30.570
Januwalla, Alia [FH]
There are some tools and resources that can help you and help you guide at reimbursement and compensate compensation guidelines.

0:45:30.840 --> 0:45:44.330
Januwalla, Alia [FH]
So reimbursement would be the repayment for out of pocket expenses, for example, childcare, parking, mileage related to engagement of an activity and compensation is something awarded to someone in exchange for a service.

0:45:44.340 --> 0:45:56.570
Januwalla, Alia [FH]
And so this may take the form of an honorarium or in kind gift, but it's typically used in in thanking patient partners for their involvement with research.

0:45:56.940 --> 0:46:4.220
Januwalla, Alia [FH]
And so these are a few tools that can be used to support to you in budgeting for patient and public engagement in health research.

0:46:7.370 --> 0:46:12.20
Januwalla, Alia [FH]
I've also linked a few tools here for actually how to recruit patient partners.

0:46:12.470 --> 0:46:16.580
Januwalla, Alia [FH]
Reach BC is the great is the best first place for you to go.

0:46:16.870 --> 0:46:24.640
Januwalla, Alia [FH]
It is BC's on for it's it's a recruitment platform in BC for participants and patient partners in health research.

0:46:24.650 --> 0:46:31.610
Januwalla, Alia [FH]
Research and so you can look for both participants for your research study as well as patient partners.

0:46:33.390 --> 0:46:37.900
Januwalla, Alia [FH]
Patient Voices Network is also a great Ave for recruiting patient partners.

0:46:38.50 --> 0:46:43.360
Januwalla, Alia [FH]
If you're looking at something that's more advisory or more Qi, focus for patient partnership.

0:46:43.430 --> 0:46:50.690
Januwalla, Alia [FH]
Then I would recommend patient voices, but you can also look at community organizations and health networks to recruit patient partners.

0:46:53.440 --> 0:46:59.110
Januwalla, Alia [FH]
And a quick note is that if you're struggling with recruiting patient partners, it's also something that the BC support unit can help you with.

0:46:59.120 --> 0:47:8.650
Januwalla, Alia [FH]
So our team can chat through some suggestions of how you might be able to recruit patient partners based on your unique study and yours questions.

0:47:11.910 --> 0:47:19.510
Januwalla, Alia [FH]
Umm, these are just a few a few links around equity, diversity and inclusion in research.

0:47:19.520 --> 0:47:38.700
Januwalla, Alia [FH]
It is a core part of I'm of Howard viewing research and how our viewing patient oriented research at something that we're also evolving on in terms of how we as a unit and as a team can be advancing equity diversity and inclusion in the research that we're supported.

0:47:42.270 --> 0:47:54.990
Januwalla, Alia [FH]
I've also linked to some tools here for creating culturally and socially safe environment and so so just some other tools and that that we can use to chat tangibly, create a more equitable and inclusive environment.

0:47:59.160 --> 0:48:10.870
Januwalla, Alia [FH]
This is a fantastic resource that was actually developed by the BC support unit with patient partners and it was designed to show the many ways in which patient partners and members of the public can be engaged on a research team.

0:48:11.120 --> 0:48:25.120
Januwalla, Alia [FH]
So I'd recommend clicking on the link if you hover on each of these activity areas, it'll show a whole number of example ways that patients can be engaged for these various stages that might occur on the research journey.

0:48:31.500 --> 0:48:39.370
Januwalla, Alia [FH]
So Fraser Center has been around for about and six to seven years.

0:48:39.920 --> 0:48:53.60
Januwalla, Alia [FH]
Yeah, 6 to 7 years and we've been supporting over 100 research projects since we first started and we've also supported 129 patient partners in research and governance activities.

0:48:55.50 --> 0:49:7.670
Januwalla, Alia [FH]
Uh, what's also really awesome is that three of those studies were actually patient directed and so patient partners came to us saying, you know, we really wanna find research partners to work with about what we're passionate on.

0:49:7.780 --> 0:49:13.540
Januwalla, Alia [FH]
And we were able to make that happen for three of those studied for three patient directed studies.

0:49:20.740 --> 0:49:25.470
Januwalla, Alia [FH]
Our patient partners are uniquely involved and our operations and governance activities.

0:49:25.680 --> 0:49:42.930
Januwalla, Alia [FH]
So we have a researcher ready Patient Partners Group, which is a group of research ready patients who want to be more actively engaged and shaping research processes and agendas and assisting with feedback to researchers on research ideas, assisting with recruitment, et cetera.

0:49:43.780 --> 0:49:55.940
Januwalla, Alia [FH]
We also have a core oversight committee that provides strategic, operational and fiduciary oversight for our center and is composed of representatives from SFU, Fraser Health and patient partners.

0:49:57.290 --> 0:50:7.870
Januwalla, Alia [FH]
Our patient partners also really support us and shared decision making when it comes to activities that our center might put on and these are some projects that we've supported.

0:50:7.880 --> 0:50:11.900
Januwalla, Alia [FH]
So I just wanted to provide a few examples from projects we supported.

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Januwalla, Alia [FH]
So this project was thought up by some South Asian researchers and health providers in the region, who understood that South Asian engagement and research was severely lacking, despite a huge South Asian population being affected by health issues.

0:50:26.490 --> 0:50:31.390
Januwalla, Alia [FH]
So there was a real gap that they weren't really being accounted for in the types of research that we were focusing on.

0:50:33.750 --> 0:50:46.970
Januwalla, Alia [FH]
Our team helped support this project team with planning, recruitment of patient partners and participants and facilitating a priority setting process to improve the quantity and quality of health research for the community.

0:50:49.790 --> 0:50:53.870
Januwalla, Alia [FH]
We supported a strategy for and facilitated goal setting activities.

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Januwalla, Alia [FH]
And we also supported knowledge dissemination activities.

0:51:0.240 --> 0:51:15.220
Januwalla, Alia [FH]
We were able to establish meaningful relationships with community and worked with community to recruit at community events, local places of worship to recruit 238 participants to complete priority setting practice surveys.

0:51:20.780 --> 0:51:25.570
Januwalla, Alia [FH]
Another example of this project is the fracture liaison service.

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Januwalla, Alia [FH]
This is led by Doctor Sonia Singh at Fraser Health, who identify that there was an osteoporosis care gap.

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Januwalla, Alia [FH]
Doctor Singh knew that there was an evidence based model called the Fracture Liaison Service that was recognized as an effective model to address some osteoporosis care gap.

0:51:46.800 --> 0:51:59.370
Januwalla, Alia [FH]
And Doctor Singh used implementation science methods to implement to assess context, adapt to the fracture lease on service, implement it and evaluate its effectiveness.

0:52:0.880 --> 0:52:9.120
Januwalla, Alia [FH]
There were a lot of challenges faced in implementing fracture liaison service, but having a patient partner on the team was really critical to its success.

0:52:10.60 --> 0:52:25.20
Januwalla, Alia [FH]
Patient partners were involved in identifying the problem priority setting, adapting the fails to make it more relevant to their experiences, and they helped foster legitimacy and buy in with decision makers and leadership.

0:52:26.270 --> 0:52:31.560
Januwalla, Alia [FH]
And ah, so that this this intervention could eventually be implemented.

0:52:32.500 --> 0:52:43.510
Januwalla, Alia [FH]
This team has now received a grant to scale and spread FLS across BC, but I've also received a grant to develop health policy related to the fracture liaison service for BC.

0:52:48.560 --> 0:52:55.980
Januwalla, Alia [FH]
Umm, so our center BC support unit and Fraser Center does offer a number of webinars, online training resources.

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Januwalla, Alia [FH]
And and and a website that you can learn more here.

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Januwalla, Alia [FH]
Uh, we as a team provide services and supports in poor and KT, so we can support patient engagement by discussing frameworks, developing plans.

0:53:14.920 --> 0:53:18.290
Januwalla, Alia [FH]
I'm sharing best practices for compensation and reimbursement.

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Januwalla, Alia [FH]
I can also provide support in knowledge mobilization and we also offer tailored workshops to research teams depending on their needs, so get in contact with us to learn more.

0:53:33.650 --> 0:53:39.870
Januwalla, Alia [FH]
And again, if you'd like to contact us and these are all of our socials, this is a website for the BC support unit right here.

0:53:40.880 --> 0:53:42.520
Januwalla, Alia [FH]
And thank you so much.