

Workshop Companion

Demystifying Authentic Patient Engagement

Practical tips for success



Patient
Voices
Network

Demystifying Authentic Patient Engagement

This primer is a companion document to a workshop of practical tips for engaging patient partners in your work. We've compiled some of the best and brightest resources, with some follow along commentary, to guide you along the path of authentic patient engagement. By no means is this an exhaustive list of resources or tips; rather, it's a small representation of the wealth of information out there to assist you in your efforts.

As always, the Patient and Public Engagement Team at the BC Patient Safety & Quality Council is available to discuss your proposed plans and provide you with some assistance in developing your engagement strategies. You can find our contact information on our website at PatientVoicesBC.ca.

Table of Contents

Frequently Asked Questions	1
Checklist for Attitudes about Patients and Families as Advisors	2
Preparing Your Team	5
Authentic Engagement Principles	7
Identifying Patient Partners	8
Tips for Engaging Marginalized Populations Engagement: Tips For Facilitation	9
Helpful Resources	10

Frequently Asked Questions

When you first begin engaging patient partners, it's understandable if you are nervous. We've compiled some frequently asked questions that may help you in your team discussions.

What if the patient's suggestions are complicated, or if they'd need too much time and money?	Patient partners are, for the most part, aware of the challenges faced by health care leaders and decision makers, and they realize that they must balance safe and quality care, system strains and increased costs. To ensure a good understanding of those limitations, setting out clear parameters and a clear overview of the current state will assist you in making the engagement meaningful.
We're so busy. What if people on my team don't see the value?	It's important to recognize that health care partners set the agenda, expectations and key questions to ask the patient partners. The more time you put into preparation, the better chance of a beneficial experience for both your team and the patient partner. We find that getting patient partners involved in co-creating your activity creates better understanding and shared leadership for your engagement.
What if the patients' health care experiences were negative and they are struggling to move forward?	Most patients want to ensure that their experiences are not duplicated, and they are thrilled to have an opportunity to share how they were impacted, in a teachable moment. It's an opportunity to share lived experiences and perspectives in order to contribute to broader and bigger picture conversations and efforts to improve patient safety, quality care and the patient experience.
We discuss confidential information. How do we know that this will be kept "in house?"	All health care partners are encouraged to have discussions at the start of an engagement opportunity to ensure the importance of respecting the sensitive nature of the conversations that take place as part of their involvement. In most cases, it is encouraged to have an agreement signed by all patient partners to ensure that the information is kept confidential. An example of this is the Patient Voices Network's Volunteer Agreement, found at PatientVoicesBC.ca/patient-partners/volunteer-agreement/

For testimonials from some of PVN's patient and health care partners, visit PatientVoicesBC.ca/health-care-partners/testimonials/

If you would like detailed information on how to address any hesitations you may have, take a look at the briefs created by the Canadian Foundation for Healthcare Improvement that provides some plain language tips and tools. There are six in the series: bit.ly/2qrWsd7

As described earlier, preparation is the key to authentic engagement. Discussing as a health care team your assumptions, attitudes and commitment towards this shift in relationships with patients is an important step in team readiness. A good guide to having this discussion is from the Institute for Patient- and Family-Centered Care. These questions can serve as a self-assessment and a discussion tool for your team in the preparation stage for authentic engagement.

CHECKLIST FOR ATTITUDES ABOUT PATIENTS AND FAMILIES as Advisors

Use this tool to explore attitudes about patient and family involvement in their own health care and as advisors and/or members of improvement and redesign teams. It can be used for self-reflection and as a way to spark discussion among staff and physicians before beginning to work with patients and families as members of advisory councils, and quality improvement, policy and program development, and health care redesign teams.

Answer and discuss the following questions:

At each health care encounter:

- Do I believe that patients and family members bring unique perspectives and expertise to the clinical relationship?
- Do I work to create an environment in which patients and families feel supported enough to speak freely?
- Do I listen respectfully to the opinions of patients and family members?
- Do I encourage patients and family members to participate in decision-making about their care?

At the organizational level:

- Do I consistently let colleagues know that I value the insights of patients and families?
- Do I believe in the importance of patient and family participation in planning and decision-making at the program and policy level?
- Do I believe that patients and families bring a perspective to a project that no one else can provide?
- Do I believe that patients and family members can look beyond their own experiences and issues?
- Do I believe that the perspectives and opinions of patients, families, and providers are equally valid in planning and decision-making at the program and policy level?

If you have experience working with patients and families as advisors and/or members of improvement or other teams, answer and discuss these additional questions:

- Do I understand what is required and expected of patients and families who serve as advisors and/or members of improvement or other teams?
- Do I clearly state what is required and expected of patients and families in their roles as advisors?
- Do I help patients and families set clear goals for their role?
- Do I feel comfortable delegating responsibility to patient and family advisors and improvement team members?
- Do I understand that an illness or other family demands may require patients and family members to take time off from their responsibilities on these teams?

Preparing the Team for Engagement

After having those discussions to confirm that you are all on the same page for developing a new relationship with patient partners, it's time to confirm the details of the engagement. A great place to start is with this resource:

Key Questions to Ask When Planning a Patient Engagement

- 1. What is the aim of engaging patients in your project?** It is important to define the aim to make sure everyone is clear on the main objectives i.e. what are you trying to achieve by engaging patients?
- 2. What role will the patient partners play?** Using the spectrum of engagement as a guide, where does this placement fall (inform, consult, involve, etc.) Visit the International Association of Public Participation website (www.iap2.org) for more information.
- 3. What is the best technique to achieve your aim?** The International Association of Public Participation provides helpful information on engagement techniques. Some examples of techniques include surveys, focus groups, world café, or advisory committees.
- 4. How many patients do you need to engage and when?** This will depend on your previous answers. When appropriate, it is recommended by the BC Patient Safety and Quality Council that you seek a minimum of 2 patient partners as early as possible in the process and planning.
- 5. Who are you looking for?** Give thought to patient partner specifications such as demographics (age, cultural background, gender), geographic region, specific health conditions or experience with particular aspects of the health care system.
- 6. Who will support the patient partners within your organization?** An internal person should be designated as a point of contact to help prepare and support patient partners during their engagement.
- 7. What resources do you have available to support patient engagement?** (i.e. can you pay for mileage, parking, childcare, meals?) Be clear with patient partners what expenses will be covered and your process for reimbursement.
- 8. Do you have background documents** (e.g. Terms of Reference and past meeting minutes)? This will allow better understanding of the goals, priorities, and current focus of this work?
- 9. Privacy and confidentiality are important to both patients and health care partners.** Do you have a confidentiality agreement that patient volunteers will sign prior to participating? Do you have a way to emphasize to patient partners that their input and perspectives will remain privileged within this opportunity?
- 10. How will you know if you are achieving your aim?** What measures will you use to evaluate the engagement from your perspective and from the patient's point of view? Patient Voices Network staff will ask both Health Care partners and patient partners to complete a survey after the first event and at the end of the project, but you may wish to think about how you might include patient partner feedback in your final product.
- 11. How will results or outcomes be reported back to patient partners** (I.e. Closing the Loop)? Sharing outcomes from engagements with patient partners is encouraged as a best practice and part of authentic patient engagement.

You can also use the following questions to support your team in clarifying goals, objectives and overall readiness for successful engagement! Keep in mind that you can have more than one reason for wanting to engage patients & families in a decision-making process. Be aware that the more complex and multi-faceted the decisions are, the more ambitious and resource intensive your engagement plan will need to be.

MAKING THE DECISION TO ENGAGE

Overall: Ensure that the Engagement Goal Benefits Patients & Families!

Is the scope and intended goal of your project(s) to:

- Improve service design and/or the process of receiving care?
- Ensure appropriate treatment and care?
- Improve health outcome?
- Reduce risk factors and prevent ill health?
- Improve safety?
- Improve patient experience?
- Set priorities for action?
- Strengthen accountability?
- Ensure access to treatment?
- Improve transitions between services?

If you cannot say “yes” to any of these broad goals, please reconsider your current plan for engaging patients and families to be more specific about your efforts.

Principles for Authentic Engagement

Meaningful patient and public engagement doesn't happen by accident - it takes deliberate effort and a commitment to remain open and collaborative throughout the process. To help guide you in these efforts, please consider the following Principles of Authentic Engagement and ask yourself whether you are including patients in a way that is of value to you, to them, and to our health care system.

People affected by a decision are invited to be involved in the process.

As leaders and decision-makers, we acknowledge that it is important for patients and other stakeholders to have their voices and opinions heard when there is a decision that will impact them in some way.

Health care partners commit that the patient partners' input will contribute to the outcome.

We engage patients at a point where their input can make a difference, and the expectations around how this input will be used will be communicated early on in the process.

Sustainable decisions are possible only when the needs of all partners have been recognized.

Our goal should be to find solutions and improvements that will be supported both now and in the future. By engaging patients in our work from the earliest stages of improvement, we can see where we need to go to achieve a mutually-agreeable solution that will best serve everyone's needs.

Diverse perspectives are sought and invited to participate.

We are comfortable hearing from a diverse range of opinions – even if they are not in agreement with what we want to see. This helps establish a mutually-agreeable and widely supported decision.

Patient partners are provided with the necessary information to participate fully.

While patients bring a unique perspective to our work, we cannot assume that they are as well-versed in the technical aspects of health care. Care should be taken to ensure that they are given enough support and information so that they can participate in a meaningful way.

Participants are updated throughout the process about how their input affected the outcome.

By inviting patients into our work, we ensure that our patients receive regular updates on how the decision is progressing and how their input and expertise was used. Closing the loop in a timely manner helps create value for their contributions.

Identifying Patient Partners

Once you have a plan in place, and have reached out to find a patient partner, you will be faced with determining what your criteria is for identifying the best patient partner to join your team. This process will be dependent on what the best fit for your goals and objectives would be as well as whether you want to meet potential patient partners in person, or via telephone. Here are some helpful questions that you can use to discuss involvement with your engagement with a patient partner.

Why do you want to volunteer?	Your questions/ considerations?	How do you want to interact?
<ul style="list-style-type: none"> • Why are you interested in being a Patient Volunteer? • Do you have a recent healthcare experience, or a past healthcare experience that was important to you? • What area of healthcare did your experience take place in? • Were you the patient, family member or friend of a patient or a visitor? • What unique life experiences or perspectives would you bring to your role? • What are your areas of interests? Areas that you wish to contribute and/or develop skills in? • How do you think you can best contribute to our work? • Do you feel able to share your experiences in ways that others can learn from? Can you provide an example? • Do you have any concerns about the emotional experiences you may have in sharing your story? 	<ul style="list-style-type: none"> • Tell me a bit about yourself. (i.e. what do you like to do in your free time, what things are you interested in, where are you from?) • Is there any other information that you think might be important for us to know about you? • Are there any kinds of accommodations or additional support from us that will help you in your volunteer experience? • Do you bring the perspective of someone from an economic, social, cultural, economic or geographically group that is well represented or not well represented? • Are you a member of an underserved or underrepresented population? If so, which population is that and would you feel comfortable representing their perspective? • What other volunteer work have been involved with and with which organization(s)? Tell me more about it... 	<ul style="list-style-type: none"> • What is your preferred method of contact – email, phone, mail? • What communications and computer technology is available to you? (i.e. do you have access to a phone? The internet?) • Are you able to travel? (i.e.: within your city, general region?) • How often may we contact you? • How do you prefer we touch-base? (Phone or e-mail?) • Do you have any questions I can help answer right now?

Source: Adapted from a Resource Toolkit for Engaging Patient and Families at the Planning Table, Alberta Health Services

It is important to consider benefits and challenges when engaging hard to reach populations. Please use this chart as a guide in your consideration of what activity to choose. For more information on the Spectrum of Engagement: www.iap2.org

Consult: involves obtaining patient feedback on analysis, alternatives, and/or decisions that planners have already created.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Opinion poll	<ul style="list-style-type: none"> a paper or electronic tool with a number of preselected options presented to participants for them to select their preference usually a single event 	<ul style="list-style-type: none"> good for sensitive or controversial topics quick, requires limited commitment 	<ul style="list-style-type: none"> literacy barriers language barriers qualitative information and experiences are limited 	soliciting opinions of patients on specific topics
Suggestion/ feedback box	<ul style="list-style-type: none"> submission of suggestions, comments, or feedback at the site of care delivery can ask for feedback on questions about specific topic or ask for any and all feedback 	<ul style="list-style-type: none"> can be anonymous patients can raise issues with existing services good for sensitive or controversial topics allows patients to set the agenda 	<ul style="list-style-type: none"> excludes populations who are not currently accessing the service may not be clear mechanism to address concerns raised 	soliciting broad feedback from clients or trying to learn about issues facing patients that planners might not be aware of
Comment forms and surveys	<ul style="list-style-type: none"> a paper or electronic tool that participants fill out by themselves or with assistance used to gather opinions, feedback, and basic information that is easily quantified. usually a single event 	<ul style="list-style-type: none"> can be anonymous good for sensitive or controversial topics quick, requires limited commitment 	<ul style="list-style-type: none"> literacy barriers language barriers qualitative information and experiences are limited 	soliciting opinions, feedback, and other simple information on specific questions or topics
Forums, public meetings, town hall meetings	<ul style="list-style-type: none"> a large group convenes to discuss their opinions, ideas, preferences, and experiences often includes speakers who present information about the subject followed by audience participation can be a single event or recurring 	<ul style="list-style-type: none"> open door to everyone may be inviting many people can participate potential to have great diversity in the room and for people to hear different perspectives 	<ul style="list-style-type: none"> if open to general public, marginalized groups may be less likely to participate may amplify the differences in participants' abilities in large groups some groups of people are less likely to participate may not be good for sensitive topics 	soliciting input from a large number of people
Focus groups	<ul style="list-style-type: none"> a group of people (5-10) gathered together to discuss questions that are posed by a facilitator used to gather information about opinions, ideas, preferences and experiences not used to build consensus, but rather to collect information usually a single event 	<ul style="list-style-type: none"> can be good for sensitive topics discussion between participants generates new ideas elicits experiential evidence not anonymous or completely confidential 	<ul style="list-style-type: none"> some participants may dominate the discussion determining who gets invited to the focus group can shape the feedback received if language barriers are an issue, interpreter(s) will be required 	<ul style="list-style-type: none"> in-depth information required from the patients. benefits to bringing patients together to discuss the topic are foreseen.
Interviews	<ul style="list-style-type: none"> one person, or a few people, answering questions posed by an interviewer. There is no discussion between participants in group interviews used to gather information about opinions, ideas, preferences, and experiences usually a single event 	<ul style="list-style-type: none"> good for sensitive topics elicits experiential evidence allows more flexibility in location than a focus group as interview can go to each participant 	<ul style="list-style-type: none"> no discussion between participants means less opportunity to flesh out ideas more time consuming for planner to book and conduct individual interviews if language barriers are an issue, interpreter will be required 	<ul style="list-style-type: none"> in-depth information from the patients is required the topic is sensitive sufficient time and resources are available to conduct interviews

Involve: means working with patients during the planning process to ensure their concerns are understood and considered in the planning. This means that the planners do not yet have a set of alternatives about which they are asking patients' for their opinion, but rather patients are contributing to creating the alternatives.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Workshop	<ul style="list-style-type: none"> convening a group of people to work on an issue if the group is large, the participants are divided into smaller groups within the workshop, a number of strategies may be used to work through activities may be single or recurring events 	<ul style="list-style-type: none"> a number of different strategies can be used to encourage discussion and joint problem-solving discussion between participants generates new ideas elicits experiential evidence 	<ul style="list-style-type: none"> some participants may dominate the discussion determining who gets invited to the workshop can shape the feedback received if language barriers are an issue, interpreter(s) will be required 	<ul style="list-style-type: none"> in-depth information is needed from the patients potential for patients to help generate ideas for elements of the program or alternative ways of delivering services benefits to bringing the patients together to discuss the topic are foreseen
Advisory committees	<ul style="list-style-type: none"> a group of people are convened to provide advice, information, feedback or guidance to a working group. The group can consist of only patients or can be a mix of patients and planners usually recurring events with the same membership throughout the process 	<ul style="list-style-type: none"> opportunity for patients to build skills deepens the understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> requires large commitment may amplify the differences in participants' abilities determining who gets invited to can shape the feedback received if language barriers are an issue, interpreter(s) will be required 	<ul style="list-style-type: none"> planners can support patients to be involved for the length of time and the depth of participation required
Patient observation of existing services	<ul style="list-style-type: none"> patients observe existing services in action to provide a patient perspective on potential areas for improvement patients may interview current patients about their experiences 	<ul style="list-style-type: none"> values the experiences and perspectives of marginalized populations 	<ul style="list-style-type: none"> may require a large commitment may amplify the differences in participants' abilities 	<ul style="list-style-type: none"> a better understanding of the patient perspective of existing services can inform improvements to the system

Collaborate: involves working with the patients in all aspects of the planning, including developing the options and alternatives to be considered and deciding upon the final program.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Participatory decision making or design	<ul style="list-style-type: none"> patients participate in the decision-making/ designing at various stages from the exploration and definition of the problem to developing solutions participation is recurring 	<ul style="list-style-type: none"> opportunity for patients to build skills deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> requires large commitment may require increased knowledge and skills by participants may amplify the differences in participants' abilities 	<ul style="list-style-type: none"> planners can support patients to be involved for the length of time and the depth of participation required to include them throughout the whole planning process.
Patient journey mapping	<ul style="list-style-type: none"> patients and providers come together to map out the healthcare journey as a way to understand the patient experience and then analyze the resulting map to look for ways to improve programs and/or systems 	<ul style="list-style-type: none"> deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> excludes people who do not have access to healthcare services 	<ul style="list-style-type: none"> a better understanding of the journey of a patient through a program or system can inform improvements by identifying the service gaps

Empower: takes this one step further and places the final decision making power in the hands of the patients.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Participatory decision making or design	<ul style="list-style-type: none"> patients participate in the decision-making/ designing at various stages from the exploration and definition of the problem to developing solutions participation is recurring 	<ul style="list-style-type: none"> opportunity for patients to build skills deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> requires large commitment may require increased knowledge and skills by participants may amplify the differences in participants' abilities 	<ul style="list-style-type: none"> planners can support patients to be involved for the length of time and the depth of participation required to include them throughout the whole planning process.
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Interviewing Patient Partners as Part of the Selection Process

For some opportunities, you may have a shortlist of patient partners, and it may be appropriate to host an informal interview to ensure that they will be a good fit for your project and that the initiative suits them. This document provides some sample questions you may use to guide that interview process.

To start the conversation, introduce yourself and your role, and review the opportunity and what you expect the patient partner role to be. We recommend that you choose between four to six questions that will help you understand their skills, background and fit for your initiative. Make it clear to the patient partner that they should only disclose what they are comfortable sharing, and remind them that their answers will be held in confidence.

Suggested Questions:

- Please briefly tell us about yourself and your interest in this opportunity
- Have you had a care experience at (organization name)? Please tell me about it.
- What types of health care services have you used?
- Can you tell us about a positive care experience? This could be an experience where you and your family felt respected or supported, where you had the information you needed and wanted, or where you and your family could participate in your health care decisions in ways that you wanted. What did the doctors and staff do that gave you confidence, comfort, and was helpful to you?
- Have you had an experience that was not so helpful? How could it have been changed or improved? How could doctors or staff have handled the situation differently?
- If you had a magic wand, and could change/improve health care for you, your family and others in the community, what changes would you want to make?
- Tell me about a great team that you were a part of. What did the team do exceptionally well? How did this impact you individually and as a group?
- In addition to your experiences as a patient, do you have other skills or strengths you would be interested to contributing to this project?

- Have you ever been in a group situation when someone had a different opinion than you?
- What was the result? Was there anything you did that was helpful?
- What if it takes a while to feel “at home” with some things that are discussed in a committee? Or what if progress coming to decisions is slow? Are you comfortable with a slow pace, or are you happiest when discussions move quickly and conclusions are reached right away? How strongly do you feel about the pace of events?
- Do you find it easy to share your opinion with a group of others? What if you have a different opinion than most of the group? What would you want to do in that situation?
- Tell me about a time when you felt you were misunderstood and people became offended or defensive. How did you handle the situation? What was the outcome?
- Tell me about a time when you had a difference of opinion with a colleague about how to solve a problem or complete a task. How did you resolve the situation?
- Would you be interested in presenting your story about your experiences to others to highlight what was helpful and what could be improved?
- Are there barriers such as transportation, food allergies, timing of meetings, language or illness that we should be aware of to assist your participation?

When you have concluded the interview, be sure to provide an opportunity for patient partners to ask you questions as well. Let them know your proposed timeline for selection and when/how they should expect to hear about a decision. Close the conversation by thanking them for their time and for showing interest in the opportunity.

Patient Engagement: Tips for Facilitation

Today's the day. You are now embarking on your patient engagement journey. It's important that you, as the facilitator, set the tone for a positive atmosphere and guide the conversation towards the aims and purposes of your initiative. The following are some helpful hints on how you can accomplish this:

- Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.
- Provide clear information about the purpose of the committee or task force and the roles and responsibilities of individual members.
- As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.
- Avoid using jargon, acronyms, and technical language, if possible. Make sure to explain and define these terms when they are used. This applies to both oral and written materials.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- Acknowledge that there will be tensions and differing opinions and perceptions.
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- If a personal story becomes very prolonged, acknowledge the power and importance of the story, and work towards ensuring that patient partners feel valued for this contribution while assisting them in moving forward with the purpose and aims of the engagement opportunity.
- When there are extreme differences in opinions or perceptions, consider:
 - Appointing a task force for further study of the issue;
 - Asking the opinion of other groups (e.g., another committee or patient/family advisory group); or
 - Delaying a decision and considering at a future meeting.

Source: Adapted from Tips for Group Leaders, Institute for Patient and Family-Centred Care <http://www.ipfcc.org/resources/tipsforgroupleaders.pdf>

Helpful Resources

There is a wealth of great organizations and resources out there to help you on this journey. This list is not exhaustive, but does provide a list of key websites and resources if you are interested in reading more.

Person-Centred Care Made Simple

<http://www.health.org.uk/publication/person-centred-care-made-simple>

Institute for Family Centred Care

<http://www.ipfcc.org/>

Better Together Toolkit, Partnering with Families

<http://www.ipfcc.org/bestpractices/better-together-toc.html>

Patient Engagement Heard and Valued

http://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf?sfvrsn=2

Institute for Healthcare Improvement

www.ihl.org

Promoting Person-Centred Care at the Front Line

<https://www.jrf.org.uk/report/promoting-person-centred-care-front-line>

Person Centred Care UK

<http://personcentredcare.health.org.uk/>

<http://personcentredcare.health.org.uk/resources/person-centred-care-health-foundation-resources>

Alberta Patient Engagement Toolkit

<http://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-engage-toolkit.pdf>

Canadian Foundation for Healthcare Improvement - Patient Engagement Hub

<http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx>

National Health Services - Involvement Hub

<https://www.england.nhs.uk/participation/>

International Association of Public Participation (IAP2)

<http://www.iap2.org/>

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