A PRACTICAL HANDBOOK

How to do patient-oriented research in forensic mental health settings

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Patient-oriented research is about making sure people have opportunities to be involved directly in research that touches their lives.

It can be a powerful way to support trauma-informed, recovery-oriented care in forensic mental health settings.

This handbook looks at five important dimensions of forensic patient-oriented research (POR) as well as core principles that are key to success. It's meant for anyone interested in forensic POR, including researchers, patients, hospital staff and more.

Following the advice in this handbook sets the stage for research projects that are equitable, safe, respectful and help build long-lasting relationships of trust in forensic settings.

Contents

About this handbook

This handbook is based on the *Guidelines for Patient-Oriented Research (POR) in Forensic Mental Health Settings* published by the Waypoint Research Institute. It offers practical advice for anyone who wants to design, carry out, or participate in patient-oriented research in forensic mental health environments.

If you want to learn more about why we recommend these specific practices, we invite you to read the **full Guidelines document**. It has references to all the research and academic sources we used to inform our approach.

The journey to here

Patient-oriented research isn't often done in forensic settings. That's partly because forensic mental health environments can be complex and partly because up to now there hasn't been much guidance about how to do it. Fortunately, that's starting to change.

In 2023, Waypoint got funding to develop a practical framework for patient-oriented research that could be used in forensic mental health settings. As part of that work, Waypoint held a Collaborative Dialogue in spring 2024 that brought together forensic patients, researchers, clinical staff, administrators and security personnel to talk about patient-oriented research in a high-secure setting. The event was one of the first of its kind in Canada and an early example of how forensic patient-oriented research can be done.

A report called ***Mapping the Way Together*** captured important takeaways from the Collaborative Dialogue and gave a roadmap for doing forensic patient-oriented research. The Waypoint team also published an academic paper on *Building Capacity in Patient-Oriented Research*.

Building on all that previous work, the *Guidelines* and this handbook were co-developed by patient advisors, forensic mental health professionals, staff at Waypoint's Patient/Client and Family Council (PCFC) and researchers. They're based on a combination of lived and living experience, best practices and lessons learned.

What makes forensic POR unique

Forensic mental health hospitals are different from other environments because they have different levels of security and are home to people with different mental health needs and cognitive abilities. In pursuing the principles and applying the practices of patient-oriented research, it's important to keep these realities in mind.

What's inside

This handbook focuses on five dimensions of forensic patient-oriented research (POR):

1. Resourcing, orientation and training
2. Compensation, consent and confidentiality
3. Relationships, shared understanding and support
4. Levels of engagement
5. Evaluation and sustainability

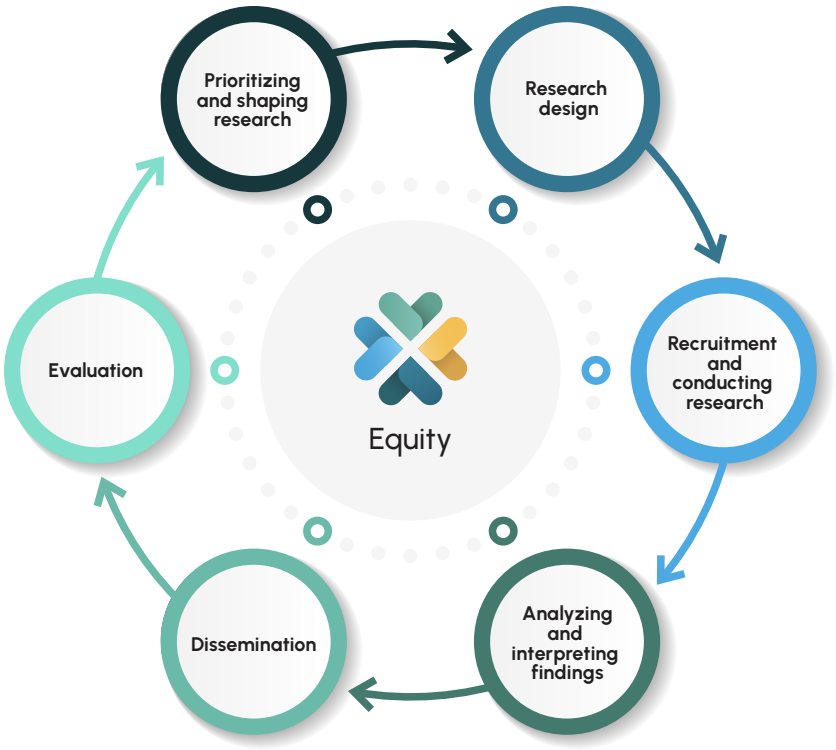
As you plan and conduct a research project using the handbook, consider where each dimension fits within a typical research cycle (Figure A). For example, relationship building and shared understanding are important throughout the entire lifecycle of a project, while orientation and training will likely occur earlier in the cycle. Considerations around compensation and asking patients to consent to being a research partner will typically arise during the shaping research or research design phase.

The handbook is not intended to be used in a sequential order aligned with traditional research cycles. Nevertheless, it is important to understand the guidance in this report as you design, plan, conduct, share findings, and evaluate your project.

Finally, because we view equity as a foundational principle that influences all stages, we have placed it at the center of the cycle so that it is considered and evaluated throughout a research project.

In addition to practical guidance, the handbook also includes links to templates, frameworks and checklists you can put to use right away. Look for this icon  to find these helpful tools.

Adapted lifecycle for forensic patient-oriented research (Figure A)



Who is this handbook for?

We developed this handbook to be used by as many people as possible. That includes:

- Researchers planning or doing forensic patient-oriented research
- Clinical, allied, security and other hospital staff who support or engage in forensic POR
- Patients serving as research partners or advisors on forensic POR projects
- Hospital administrators supporting forensic POR or embedding it in policies and practices
- Educators and trainers who develop people's POR skills
- Research ethics committees who review forensic POR protocols

Check for updates!

We're committed to keeping the forensic POR guidelines and tools up to date with new research and real-world experience. If it's been a while since you've used the **handbook**, make sure you have the most recent version.

Key terms

We've written this handbook to be as clear and easy to understand as possible. Some technical or specialized terms appear that may not be familiar to all readers. Below are the key ones to know, along with some brief definitions:

Engagement

A person's ability to contribute actively, meaningfully and collaboratively to the research process.

Epistemic injustice

Injustice and unfairness related to what someone knows or the knowledge they can access. When a person's knowledge is not considered valid or is excluded by a group or system, they are experiencing epistemic injustice.

Equity

Making sure all people are treated fairly, included, respected for what they know and benefit from similar outcomes.

Forensic Review Board

A body that reviews the status of people in forensic mental health care and makes decisions about where they should be placed.

Honoraria

Small payments or other forms of compensation that are given to acknowledge a person's effort or contribution.

Integrated knowledge translation (IKT)

A way of doing research that has researchers partner with the people who will use the research to make sure it is relevant and has a positive impact

Knowledge translation

Sharing research findings with people who can use them, and supporting the process of making them usable.

Meeting minutes

Written notes from meetings that remind people of what was discussed and any agreements reached or actions to be taken.

Participatory research

Research that involves the people affected by an issue in studying it to drive action or change.

Patient participant
A patient who takes part in a research project.

Patient partner
A patient who takes part in a research project as a co-researcher or advisor.

Patient-oriented research (POR)
Patient-oriented research ranges from information-sharing about research to consultation, collaboration and true partnership in research by researchers and patients together. In forensic mental health settings, POR is known as 'forensic POR'.

Patient/client family council
A council that partners with mental health and addictions services providers to improve people's experience of care. The Patient and Client Family Council (PCFC) at Waypoint is a non-profit organization with staff and volunteers who have personal experience with the mental health and addictions systems.

Peer researcher
Somone with personal experience of an issue who contributes to research on that issue.

Peer support
Support provided by people with lived and living experience to each other.

Plain language
A way of writing and speaking that is simple, clear, non-technical and meant to be understood by the broadest possible audience.

Relational security
Safety and security practices based on staff knowledge of a patient and their environment.

Research participant
Someone who takes part in a research project.

Trauma-informed approaches
Approaches to care and working with others that recognize the impacts trauma and other forms of suffering or inequity may have had in their lives, and that shape how they act.

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Everyone has a place at the table

Embedding equity in research

Forensic mental health patients are often very vulnerable people. Historically, they have been excluded from conversations about their own care and treatment, and have experienced harm as a result. That's why the starting guideline for forensic patient-oriented research is to make sure equity is built into every stage of the research process.

What does 'equity' mean?

According to the Ontario Support for Patient-oriented Research (SPOR) unit: "Equity means fairness. Health equity means fairness in health outcomes and throughout the health sector including within health care, training, education, and research."

To establish equity, this handbook and the *Guidelines for Patient-Oriented Research (POR) in Forensic Mental Health Settings* draw on the **Ontario SPOR SUPPORT Unit (OSSU) Equity Framework**. Part of that is encouraging research teams to ask a few key questions right from the start of any project:

Whose knowledge counts?

Whose needs are being prioritized?

Who is at the table, who is missing — and why?

Once those questions have been answered, research teams should also do the following:

Think about equity in research early, often and consistently.	This means doing equity assessments as soon as you start thinking about a research project and keeping them going through all the stages: design, data collection, analysis, knowledge translation and evaluation.
Use the OSSU Equity Framework to stay focused on equity.	The framework can help with: ▪ Building inclusive and diverse teams ▪ Building equity-oriented partnerships ▪ Putting equity at the centre of research, capacity building, training, knowledge translation and the impacts you want to achieve
Have regular equity check-ins.	Build these into the process over the course of the whole project. Note how decisions are made, who is at the table, and how power and privilege are being navigated. The OSSU Equity Framework can support this part of the process, too.
Create safe conditions and be accountable for harms.	Many people in forensic settings have been harmed by institutions and systems in the past. They need safe conditions to be involved in research, and research teams need to be accountable when harms occur. This requires trust-building and valuing the time, knowledge and vulnerability of the people involved.

The Center for Implementation's **equity-guiding questions** give helpful prompts to ensure equity stays front-and-centre at every stage of a research project.

Equity is about understanding where people come from

That makes it important to consider how social and structural determinants such as criminalization, racism, colonialism, gender, disability, poverty and more affect the research process and the experiences of people involved.

OSSU equity framework

Equity-guiding questions by The Center for Implementation

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Stick to your principles

Rooting research in strong values

When forensic patient-oriented research is principles-based and built on solid values, engagement is stronger and the space is created for patients to feel genuinely involved. The following should be built into every part of a patient-oriented research project:

Dignity	Protecting people's dignity is the essence of forensic POR —recognizing their human rights, honouring them as individuals, and not defining patients by their histories.
Respect	Mutual respect comes from making an effort to establish authentic, equal partnerships where patients' voices are heard. People's input should be taken seriously and understood free from bias, judgement or discrimination.
Inclusion	Involve a diversity of patients including Indigenous people, Black people and people of colour, 2SLGBTQ+ individuals, persons with disabilities, and those living with intersectional identities. Make sure all engagement is genuine — that people have real opportunities to contribute and aren't just 'token' participants. And check in regularly to confirm patients still want to be engaged and feel able to keep participating.
Collaboration	Forensic POR is a collective endeavour. Build an interdisciplinary team of patients, hospital staff, PCFC staff and researchers.
Trust	Be clear that what patients share during research engagement will not be used against them or negatively affect their Review Board status, levels of activity in hospital or treatment plans. Some may be skeptical about this, but it's still important to send the message.
Transparency	Communicate honestly and clearly and be upfront about goals, expectations, processes and how patients' input will be part of the research process.
Quality	Focus on high-quality research that matters to patients, avoids reinforcing stereotypes or stigma, is clear about any underlying assumptions, and ensures findings are shared first with the people involved. Structure research so that patients are the first to benefit, and explain how they can expect to reap those benefits.

Who can take part in forensic POR?

The short answer is 'anyone'. Start from the position that all patients are capable of engaging in research. Don't rely solely on staff opinions about who should be involved — though you can consider them. And recognize that from day to day a patient's ability to participate may change. Adapt accordingly.

Reflective questions to bring underlying assumptions to light

Toolkit for engaging people with lived experience in research at University Health Network

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Dimension 1: Resourcing, orientation and training

Laying the right foundations

1

Resourcing

Resourcing in forensic patient-oriented research is about making sure all the right supports are in place for safe, authentic patient engagement from start to finish. Those supports include money, knowledge and organizational structures. Thinking about resources usually starts when the research team applies for a funding grant.

The two main resourcing considerations are setting aside a portion of the budget for patient engagement and time-planning.

Budgeting for patient engagement

A benchmark is to set aside 10% of the project budget for patient engagement to cover:

- Compensation and remuneration
- Connection-building activities involving patients, members of the public and other organizations, including social or informal gatherings and knowledge exchange events
- Staff time to lead, support, and mentor.
- Supervision and coordination
- Recruiting an extended cohort of patients to bridge absences or drop-offs
- Physical resources such as meeting space and communication technologies
- Training and skill-development opportunities
- Various knowledge-sharing formats (such as plain language summaries of academic papers, oral presentations and more)

A note about compensation

Compensating patients for their time and contributions to research activities is important. Ideally this compensation will be financial, though it can take other forms if financial payment is not an option.

Effective time planning

Research activities should be planned around patients' routines and treatment schedules. As the project goes on, it's a good idea to get feedback from everyone involved about what's working and opportunities for adjustment.

It's also critical to plan extra time at every project stage for:

- Patient support to make sure everyone understands the project and what's involved
- Trust-building with patients and staff through informal conversations ("just talking")
- Patient recruitment and ongoing engagement
- Generating practical supports such as printed materials in advance of meetings, helping patients with reading and writing if needed, etc.
- Sharing information in a variety of formats and to suit diverse audience needs, and maintaining communication during gaps or delays
- Navigating institutional processes such as Research Ethics Boards, patient employment contracts or agreements, etc.
- Unexpected disruptions such as last-minute cancellations, incidents on hospital units, limited meeting space, or individuals' mental health needs.

Websites for suitable funding streams for patient-oriented research teams:
PASSERELLE - National Hub in Capacity Development for Patient-Oriented Research
Canadian Institutes of Health Research - Strategy for Patient-Oriented Research

Orientation and training

When patient-oriented research is truly an embedded practice, everyone in the forensic health setting will have a basic understanding of what research involves and how to do it in a patient-oriented way. This requires dedicated awareness-raising and educational efforts among patients, staff, clinicians, administrators and others.

Anyone involved directly in forensic patient-oriented research projects will need more specific and in-depth training. For patients, this training should be flexible and adaptable to meet different needs, strengths and experience levels.

To set up a forensic POR project for success, research teams should do the following:

Find out where patients are starting from	Get a sense of what patients know about research, how ready they are to engage in it, and why they want to learn about it. Some people may be personally curious; others may want to achieve a specific goal.
Explain the project clearly	Make sure patients understand the study's focus, objectives, scope and potential impacts so they can make an informed decision about engaging and feel prepared to contribute meaningfully. Provide opportunities for patients to co-define study aims, scope and impacts at the outset.
Teach the fundamentals	Train patients in any health or mental health concepts that are relevant to the study — and explain what makes them so. Introduce core concepts of forensic patient-oriented research, explain why patient engagement is important, and impart the necessary skills. Key concepts include the research cycle, research design and methodologies, common research terms, and research ethics including confidentiality and consent.
Focus training on patients' roles	Outside of the fundamentals, offer training that's specific to the role(s) patients will play in the project. This may include developing practical skills in participant recruitment, qualitative interviewing, data analysis, creating tables and graphs, and more.
Cultivate strong communication skills	Help patient partners strengthen their abilities in storytelling, public speaking, presenting findings, answering audience and peer reviewer questions, and drawing on their own lived or living experience. It's also valuable to provide some training in conflict resolution and respectful team dynamics.
Foster self-advocacy and self-reflection	To whatever extent possible, help patients develop the skills to advocate for themselves, be confident, think critically, listen actively and facilitate groups. Provide some training in self-reflection and bias awareness, and encourage patients to reflect on their assumptions as they are able.
Set expectations	Clarify standards of respect, boundaries and confidentiality, and outline appropriate interactions and professional conduct for working alongside other patients and hospital staff. Consider whether group- or individual-based engagement is better suited for the goals and structure of the project.
Solicit feedback and acknowledge achievements	Invite patients to reflect on key takeaways and suggest ways to make training content, workloads or formats even better. Provide patients with some form of recognition when they complete training, such as a printed certificate.
Establish a patient–staff expert group	This group should meet regularly and help raise awareness of forensic POR. Patients can support the onboarding of new participants.

Facilitate involvement when needed

Some patients may not fully trust the research process. Others might have a hard time balancing research with their daily lives. In those cases, consider having a trained, neutral facilitator help support patients' ongoing involvement.

When to schedule training

Align training with key milestones in the research process. Generally, this will fall into three buckets:

1. Pre-research orientation sessions to establish foundational knowledge
2. Training specific to each phase of the research project
3. Training that happens in parallel with the project as it goes on (to minimize gaps between learning and how it's applied, ensuring patients acquire the knowledge and skills they need when they need them)

The pros of continuous learning

Patients report a strong preference for training that happens in parallel with a project as it unfolds, with learning integrated throughout the research process.

Training formats and approaches

The aim of training should be to build understanding, not just deliver information. Best-practice formats and structures for training patients in forensic POR include:

- Offering multiple workshops so patients can revisit and build on concepts over time. This can involve in-depth discussions about content that's been covered previously to improve comprehension and retention.
- Incorporating team-based, one-on-one, in-person and e-learning formats tailored to patients' preferences, abilities and security requirements. If technology is used, make sure patients have access to it. If they don't, provide alternative ways for them to engage.
- Using a mix of teaching strategies to suit different learning styles, including interactive approaches, traditional lectures, and informal or 'on-the-job' learning.
- Using plain language for training and incorporate different presentation formats, visual aids, tools such as illustrated dictionaries, and short videos.
- Building understanding through informal conversations, group discussions and presentations, role-play (such as mock interviews), case studies and more.
- Offering additional resources and optional exercises to reinforce learning.

Other things to think about

If a research project is based on any particular concepts or theoretical frameworks, these should be introduced transparently at the beginning of the process so patients and staff can judge for themselves if they think they are valid and suitable. Some may choose not to engage in research if they aren't aligned with the underlying framework.

Different learners may need different supports, so be ready to modify training materials as needed and provide individualized assistance.

Finally, it's important to be aware that sometimes patients need to leave projects for various reasons. This is something to acknowledge and discuss at the outset and come back to throughout the research process.

Training for researchers and forensic mental health staff

Patients aren't the only ones who need training in forensic POR. Researchers and staff may need to better understand relational and trauma-informed approaches to engaging with patients and others, or to appreciate the value of patient-oriented research and related formal and informal peer supports.

These often go hand in hand with the need to address stigma and discrimination and challenge embedded ideas about patients' abilities to engage in research. Using non-stigmatizing language is key, while insights from studies of 'epistemic injustice' — the systematic undervaluing of certain voices — can help researchers appreciate patients' knowledge and perspectives and understand different communication styles, including those shaped by intellectual disabilities or personality disorders. Learning from patient/client and family councils also helps, especially for communication, active listening and the subtleties of building trust.

Last but certainly not least, it's essential for researchers to understand the realities of forensic mental health environments, including safety measures, patient sensitivities and any structural barriers to engagement. The point is not to over-emphasize any risks, which can reinforce stigma and undermine authentic partnerships, but rather to help researchers navigate tensions between engagement practices and staff and patient safety concerns.

- Self-paced patient-oriented research modules
- OSSU's Capacity Building Compendium
- Relational security staff training module
- Resources on trauma- and violence-informed care

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Dimension 2: Confidentiality, consent and compensation

Protecting rights, providing recognition

2

Confidentiality

There are two aspects to confidentiality in forensic POR. Both need to be explained clearly and upheld throughout the research process:

1. Patients research partners and advisors need to feel they can speak openly without fear of consequences. Being involved in research should not have a negative effect on their care, legal status or levels of activity in hospital.
2. Patient research participants need their personal data to be handled in accordance with ethical and legal standards.

Give options

Many patient research partners and participants will want to know that what they contribute won't be reported to the Forensic Review Board. However, some may want the choice to share their participation with the Review Board if they think it could have a positive impact. This needs to be worked out on an individual basis.

To protect confidentiality and privacy, do the following:

Explain confidentiality clearly	Do this both verbally and in writing, and work with patients to define any situations where confidentiality might be limited, such as situations where there is a clear, immediate risk someone may harm themselves or others. Ensure everyone has the same understanding of any confidentiality agreements, especially if the project deals with sensitive topics and/or involves multiple interest holders.
Put it in writing	Give patients a written explanation of how their information and views will be used, and take steps (such as advising a Clinical Liaison Officer team) to leave any references to POR engagement out of hospital reports unless a patient has specifically asked for them to be included.
Clarify relationships	Identify and make sure everyone involved understands the nature of the relationships between patient research partners and patient research participants. Some may know each other already and their relationships could last beyond the end of the research project.
Address concerns upfront	Patients may worry that written notes from research sessions could be used as "evidence" against them. Researchers should explain when and why they take notes, how they keep them secure and who will see them. Similar assurances should be given for other fears or concerns, such as letting patients know researchers do not have access to the patient charting system.
Allow for anonymous contributions	Allowing patients to use pseudonyms ('fake names') or have identifying details left out of research findings may be important to some people. Check with patients to make sure they are OK with *how* their information has been made anonymous before publishing any reports or findings. Explain that even when such steps are taken, sometimes who a person is can be guessed from anonymous information.

Stay focused on research activities	Avoid any talk about a person's previous clinical experiences or past incidents during team meetings. At the same time, be prepared for what people may want to share through the research process. Some experiences may be highly traumatic.

Consent

Like confidentiality, consent in forensic patient-oriented research also has two aspects:

1. Consent to engage as a research partner or advisor.
2. Consent to participate as a research participant.

Both must be clearly explained and continued throughout the research process.

Make sure patients are able to give their consent	This requires a shared understanding of what consent is and what's being consented to. It should happen early in the project, with regular check-ins that account for changes in health status, treatment schedules, length of stay and personal needs. Treat consent as an ongoing process, not a one-time agreement. Most importantly, make sure consent is a choice, and respect each person's preferred level of engagement. Offer support during the consent process—from caregivers, staff, or peers—to help patients better understand the purpose and process of research.
Use plain language	Explain consent in clear, simple language, avoid jargon, and make sure all consent forms and documents are easy to understand. For example, use terms like "agree" or "disagree" rather than "consent". At the same time, don't oversimplify to the point that the original meaning is changed. Depending on your audiences, consider adapting consent material into different formats (written, verbal, visual, multimedia) for different literacy levels, learning styles and mental health challenges.
Talk about consent in person	Have face-to-face conversations about consent. Be obvious about taking notes and actively invite questions about the consent process. Don't rely too heavily on digital tools.
Involve patient 'ambassadors'	Patient partners who have experience with forensic POR can support recruitment and consent discussions, helping others understand the value of research and that they will be engaged in a meaningful, worthwhile way.
Eliminate any pressure around consent	Be clear that consent has nothing to do with a person's entitlements, legal status or levels of activity in hospital. Let patients know they can decline or withdraw their consent at any time. Proactively address consent-related pressures and fears, and co-develop follow-up plans for absences so patients who step away temporarily can rejoin later on their own terms. (For example, saying, "If you miss a meeting, we'll check in next week to see if you'd like to rejoin.")

Compensation

In forensic POR, 'compensation' is any form of recognizing patient partners' contributions of time and expertise. It may be financial or non-financial, though financial compensation should be the first goal. Other options can be explored if monetary compensation isn't possible.

Whatever form it takes, compensation should be flexible and help make it easier for patients to engage in research. It should also reflect the core principles of equity, respect and reciprocity.

Consider the following when setting up compensation for a forensic POR project:

Get clear about compensation at the start	Work out the details at the beginning of the project, with agreements on what's being offered, what tasks are being compensated for, and how and when compensation will be delivered.
Be flexible	Provide monetary compensation to all patient partners and advisors if possible, but allow for alternatives such as learning opportunities, co-authorships, peer connection, fun and social activities, future employment potential or a certificate of engagement. Respect patients' choices to decline compensation or request alternative forms of recognition.
Be fair	Avoid differences in compensation for patients who are engaging and contributing in similar ways. Compensate for all relevant time, including preparation, training, practicing for presentations, meetings, and follow-ups. It's best to provide full compensation for meetings attended, even if a patient arrives late or cannot complete tasks.
Explain policies	Make sure patients understand hospital rules around compensation. If money is involved, explain any pay limits or benefit implications, such as policy-related caps on compensation or how payments might affect a person's disability or income support benefits. If a patient's total annual compensation exceeds $500, explore alternatives to prevent their benefits from being affected.
Ensure timely payments if compensation is financial	Work with the relevant finance department to ensure timely payment to avoid patient frustration or disengagement. Deposit money directly into patients' accounts: do not pay in cash. Offer alternative payment options for individuals who don't have bank accounts or the necessary documentation.

Canadian Institutes of Health Research (CIHR) patient partner compensation guidelines

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Dimension 3: Relationships, shared understanding and support

Creating the conditions for supportive collaboration

3

Relationships

Strong relationships are foundational to every aspect of patient-oriented research and should be built before work begins. That means taking the time to slowly build rapport and trust through consistent, ongoing interactions.

This isn't a formal exercise, and it has to be authentic: researchers need to spend unstructured time on units and across the hospital, attend unit community meetings, be present in shared hospital spaces, and show up at events like family picnics, holiday parties, etc. Practice active listening and establish common ground through interests such as music, sports and hobbies.

In settings where patient-oriented research teams already exist, researchers can build on those existing relationships.

Introduce research discussions gradually after comfort and trust are established. Let patients set the pace. Signs that patients may be ready to start engaging with research as a topic may include:

- Curiosity
- Questions about research
- Expressions of interest in getting involved

Create a welcoming environment that allows people to feel comfortable, to focus, and to build relationships. It may be helpful to offer food or refreshments, host dog-therapy visits, or simply hold meetings in quiet, low-distraction spaces. Encourage creativity in how welcoming spaces are designed to suit different settings.

When possible, offer patients a choice of approved meeting locations. Designate clear research spaces and work with security and clinical teams so patients from different units can attend the same sessions.

Build trust from day one

Researchers should introduce themselves to patients by name and be open about why they're on the unit. Not all patients will want to engage, so respect people's boundaries and tailor relationship-building to individual preferences, whether that means one-on-one conversations, small group discussions to promote a sense of working together, or other arrangements.

Working with staff

Researchers should seek to engage forensic mental health staff early as allies and champions. Building positive relationships creates opportunities to build on staff rapport with patients, making it easier to make introductions, coordinate activities, arrange security escorts when needed, and more.

Keep research meetings with staff separate from those with patients. Reassure patients that what they share in research meetings won't be passed on to staff. (This helps address fears about speaking freely as discussed above in the section on confidentiality.)

As the research project goes on, find out if there are staff or patient/family council members at the hospital who patients feel comfortable with, and ask if they'd like those individuals involved in any way. Patients may be more open when accompanied by someone they trust. If so, talk to the staff or patient/family council member about the patient's preference and clarify how they can support the process.

Be mindful of staff–patient complexities

In some ways, seasoned staff members may know patients especially well and have good insights into who would be suited to a particular research project and how they might like to be worked with. At the same time, some staff members may have biased views about certain patients, so it's important not to rely on individual opinions alone.

Other potential allies

When possible, and with patients' consent, build relationships with their family members, close friends or caregivers as additional supports. (If these members of a patient's extended circle are engaged, establish confidentiality expectations with them, too.)

Be aware that some patients will have few or no external contacts, and others may not always act in a patient's best interest.

Have skilled facilitators such as peer researchers help with group discussions by clarifying misunderstandings, managing dominant voices, promoting open dialogue and safe disclosure of sensitive information, and keeping meetings centred on patient priorities.

Consider hiring a dedicated project manager or someone with previous experience in secure services to help coordinate the project, support recruitment efforts and maintain ongoing engagement.

Addressing power dynamics

It is vitally important to recognize and continuously reflect on the balance of power in forensic settings and address any issues that result from power imbalances. Key considerations:

Choose facilitators carefully	While clinical team members may know patients well and have established relationships with them, they may not be the best choices to facilitate research engagement. Their involvement could increase the risk of unintentional coercion, cause patients to be uncomfortable, or discourage patients from authentically sharing their views. That said, sometimes patients may feel more comfortable supported by a familiar staff member.
Be fair and collaborative	Take steps to ensure everyone can engage equally in the research process. Allow space for debate and consensus-building, with clear processes for managing disagreements (which are inevitable), and use 'democratic' approaches like taking votes to decide issues.
Think about the impact of roles	Consider eliminating job titles or designations such as Ph.D., psychiatrist or 'expert' to avoid reinforcing power structures while still acknowledging people's unique expertise. Use titles when they bring clarity, credibility or are required. Reflect on how the differences in researcher and patient identities can affect the power balance, and how role transitions — such as from patient to patient researcher — can affect the respect and consideration given to a person's point of view. Use neutral terms like 'project advisor' to describe patients' roles in POR so that if they include the experience on their resume, it doesn't mention their use of mental health services.
Actively involve patient partners	Where appropriate, have patient partners conduct interviews, while being careful to avoid sampling and response biases.
Offer co-authorship opportunities	Invite patients to co-produce and co-author papers. This can open up new interpretations of data while reducing power differences and making findings more credible and accessible. Prepare patient partners for the peer-review process and support them by addressing external reviewers' comments.

Peer-reviewed commentary on establishing trusting relationships with patients in high-secure forensic settings

Shared understanding

Shared understanding in forensic POR means establishing a common grasp of research goals, processes, roles and boundaries. This kind of understanding is achieved through clear communication tailored to the individuals involved, allowing all patient partners to engage in research with clarity and confidence.

How to establish shared understanding:

Hold an orientation session at the start of the project	Use this time to explain the project and co-create a "shared goals agreement" or terms of reference with patient participants. This is also a good opportunity to review background documents and define roles, deliverables and expectations. Be transparent about who is involved and how they contribute, including other patient partners and advisors, hospital and patient/family council staff, researchers and other interest holders. Give the same orientation to every new patient that joins the research team.
Make meeting minutes available	Have a recorder take good notes for every meeting and make them available to all project participants afterward. This lets patients who may miss a session for health or other reasons to keep up with what's happening.
Use an integrated knowledge translation (IKT) approach	IKT is a way of doing research that has researchers partner with the people who will use the research to make sure it is relevant and has a positive impact. For forensic POR, this involves exploring patients' understanding of the research process and any experiences with past research, identifying gaps in their knowledge, and addressing those gaps in appropriate ways.
Prioritize clear and accessible communication	This can be done by: ▪ Using plain language along with pictures, recordings, software, video, posters, stickers and other tools to communicate important information, mindful of hospital safety and security protocols. ▪ Creating a glossary of common terms and acronyms. ▪ Consulting with speech and language specialists to adapt communication approaches for individuals who may experience difficulties with language, comprehension or expression.

Shared goals agreement template

Support

Support in forensic POR is about setting up emotional, practical and safety measures that anticipate people's needs and sustain their wellbeing throughout their engagement. Supports are needed for patient participants and patient research partners, and potentially others as well. Researchers, for example, may want to work in pairs for their own mutual support.

Here are some ways to provide support on forensic patient-oriented research projects:

Co-develop individual support plans	Work with patients when they get involved in the project to identify their needs and preferences. Offer access to neutral support personnel such as a staff liaison if appropriate.
Prepare patient partners for their role	Being involved in research as a patient can be emotionally complicated because it may involve listening to other people's stories, reflecting on their own experiences, and being a bridge between the research team and the patient community. Getting ready to take on that role may require preparation and support.
Establish safety and crisis plans	These plans should be used if someone is in distress, to deal with absences, or to address the complexities of overlapping roles (for example, being a research participant *and* a patient partner). They should account for potential safety risks during engagement, including how to respond if a patient makes threats towards themselves or others. Having clear protocols in advance for de-escalation, staff involvement and follow-up helps ensure that all team members know how to respond in an appropriate and trauma-informed way.
Build in debriefing time	This can be especially important after emotionally intense discussions or incidents, helping with emotional processing and consultation fatigue. End sessions early if needed and check in with participants regularly. If someone is at risk of harming themselves or others, first try to de-escalate. If that is not successful, let the unit care team know — in keeping with established confidentiality agreements.
Anticipate and deal with tensions	Patients and staff members may have thoughts about patient engagement in research that need to be addressed, and tensions can arise out of the workload burdens on patients that also need to be managed.
Hold regular check-ins	These can be one-to-one or in groups to discuss progress, needs or concerns. The principal investigator should be included whenever possible. Schedule check-ins at regular intervals or as needed. Be aware of what patients are comfortable with and don't pester. Offer phone calls as an alternative to in-person or virtual meetings to reduce barriers and make engagement less taxing.
Co-develop mentoring approaches	Discuss and co-develop mentoring arrangements with patient partners. These can be formal or informal mentorships, buddy systems or mutual support groups. Provide ongoing opportunities for patient partners to give and receive peer support.

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Dimension 4: Levels of engagement

Meeting people where they're at

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There are many different ways to engage patients in research depending on their preferences, circumstances and needs. In secure settings, engagement can vary by patient and change over time, requiring creativity, flexibility and inclusivity so that all patients have an opportunity to contribute.

Research design

Use frameworks to identify and plan the types of patient engagement that best fit the project context and goals. Be clear with patient partners about the level of engagement being requested of them and what they can expect from the research team.

Seek opportunities for people to be involved in ways they're comfortable. For example, some patient partners may be excited about interviewing other patients, while others might prefer to help develop interview questions or work 'behind the scenes' of the project.

Involve as many people as possible, including patients, in designing the project to build trust, ownership and alignment. Use engagement activities to identify patient-informed research priorities. This can be done by:

- Presenting current research topics and examples of patient-identified priorities to stimulate discussion and generate ideas.
- Asking straightforward, personally relevant questions such as, "What concerns you now?" or "What do you find helpful?" to foster meaningful dialogue.
- Ensuring that proposed research topics reflect patients' personal and current concerns. That said, let patients know in advance they might end up working on a research topic that may not feel relevant to them individually — to set realistic expectations.
- Seeking funding for a dedicated project in which patient partners consult with peers across high-, medium- and low-secure settings.

Including patients in seclusion

Patients in seclusion or unable to attend groups may be able to engage in research through one-on-one perspective sharing, with researchers bringing their contributions into team discussions.

Sharing findings

Work with forensic mental health staff to choose how to share ('disseminate') research findings. Presentations in secure settings using materials developed by patients, such as slide presentations or creative works, can be effective.

Invite patients to contribute to or co-present research findings to internal or external groups such as healthcare providers. Many academic conferences offer virtual options that allow patient partners and advisors to present without leaving the secure setting. Online dissemination options can also be useful, such as dedicated webpages.

Other creative methods to share research findings with diverse audiences include:

- Lay summaries (non-academic papers and other reports)
- "Easy read" versions
- Theatre presentations and other arts-based methods
- Papers for professional practice journals rather than research journals
- Articles written for other journals, magazines or sources of grey literature that reach service users
- In-house seminars

Adapted IAP2 spectrum for inclusive engagement by the Mental Health Commission of Canada (MHCC)

Patient-Oriented Research Level of Engagement Tool (PORLET) by Saskatchewan Centre's Patient-Oriented Research (SCPOR)

Indigenous Research Level of Engagement Tool (IRLET) by Saskatchewan Centre's Patient-Oriented Research (SCPOR)

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Dimension 5: Evaluation and sustainability

Learning from the work and carrying it forward

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Evaluation

People often think evaluation means 'measuring outcomes' but in forensic patient-oriented research it's more than that. Evaluation is about learning from the research experience. It gives researchers, patients and staff the chance to reflect, share feedback and see if the research stayed aligned with what matters to patients. Evaluation also supports closure at the end of a project and informs future planning.

Valuable steps in forensic patient-oriented research evaluation include:

Inviting feedback throughout the project	Evaluation shouldn't happen only at the end of the project. Feedback can be gathered at key points throughout, inviting people to reflect, share concerns and give input on priorities, progress and findings to keep the project on track. The key is to strike the right balance and not check in too often, which can wear down participants and feel performative or dehumanizing.
Gathering feedback on a wide range of topics	Get feedback on considerations such as accessibility, how engaged people felt, whether they would recommend the experience to others, their impressions of the research process, how easy it was for them to engage, and more. Use creative and informal approaches to gain reflections, including online or analog surveys of patients' experiences of autonomy, self-esteem, knowledge growth and self-perception through the project. Consider storytelling or guided open-ended questions for this.
Inviting feedback from staff	Give staff opportunities to reflect and share insights into what they learned, how their relationships with patients evolved, and how they used their roles to engage patients.
Proper debriefings	Implement proper debriefing practices and processes for identifying lessons learned.
Evaluating impact	Evaluate not only the engagement process and experience, but also the impact — how engagement shifted practices, decisions or outcomes. If forensic POR intends to be relational, considering who speaks, who is heard and how decisions are shared, then measurement should be relational, too. This involves evaluation of factors such as trust, psychological safety, power-sharing, recognition and sustainability.

Engage with Impact Toolkit by the Public and Patient Engagement Collaborative at McMaster University

Patient and Public Engagement Evaluation Toolkit by The Centre of Excellence on Partnership with Patients and the Public (CEPPP)

Patient-led research scorecards

Health Equity Impact Assessment (HEIA) Tool

Planning for closure

The end of any research project can be emotional for the people involved, and especially for patients who have formed new relationships and gained new opportunities for learning and growth. Set expectations up front about what will happen when the project ends, keep appropriate boundaries throughout, and be open about the difficulties people can experience when the project ends.

Sustainability

Sustainability is about extending the impact of forensic mental health research projects over time and keeping up momentum on key issues after the project is done. Here are some ways to do that:

Leverage the patient–staff expert group	Patient and staff champions can promote further research engagement in secure settings by promoting examples of relevant research, publishing testimonials and digital stories, creating posters for the units and more.
Consult with knowledge translation experts	Get advice from knowledge translation experts and patient partners on how to convert research findings into practices.
Keep research priorities fresh	Reset research priorities every five years or so to ensure ongoing alignment with patients' needs and how services evolve.
Advocate for long-term investment	Forensic POR takes time, resources and institutional commitment. Funders and academic systems don't always appreciate its value yet. Plan for sustainability by budgeting time and resources to support long-term engagement.
Create pathways for engagement beyond the hospital	Patients who leave the hospital or forensic system still have experience, expertise and perspective to contribute. Creating ways for them to continue to be involved and shape future research is important, such as a 'forensic POR alumni' association for those who are interested.
Influence policies and practices	Work with decision-makers responsible for hospital policies and procedures to ensure research findings are integrated and put into practice.

Value Proposition Playbook for Participant-Driven Research in Health Care

For more information

If you'd like to learn more about forensic patient-oriented research, visit our **website**.

Acknowledgements

We thank everyone who gave their time and thoughts to this project, whether by contributing to its early research phases, attending a café event, championing the work as a member of hospital staff or providing perspective as a patient. Thanks to all staff and leaders at the Waypoint Centre for Mental Health Care.

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Christopher Canning, Sevil Deljavan, Ryan Neil, Amber Scott, Kayla Zimmermann, Lauren Cassell, Elnaz Moghimi, Kristy Allen, Colleen Dell, Linzi Williamson, Mansfield Mela, Laura Justine Chouinard, Stephanie Junes, anonymous patient partners, and Andrew Kirkwood (editor).

Funding

Funding for this project was provided by the Canadian Institutes of Health Research through a Patient-Oriented Research Training Grant awarded in May 2023.

Suggested citation

Waypoint Research Institute (2025). *How to do patient-oriented research in forensic mental health settings: A practical handbook.*