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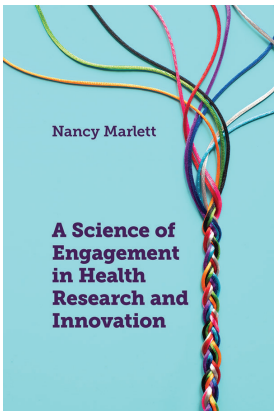

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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8

Emancipatory Methods That Engage: A Resource for Qualitative Researchers

Highlights

- Characteristics of peer research as part of a science of engagement in health research
- Discussion of the foundations of data collection, data management, analysis, and interpretation
- Quality indicators of peer research

The goal of this chapter exists within the context of making a difference in the lives of patients who are marginalized and stigmatized by the health systems trying to provide inclusive care for all those who need it. It could be called emancipatory because the patients and citizens most impacted by the need for change are involved in learning about problems in order to find solutions. This builds on qualitative research, especially community and population health research that have pioneered applied, pragmatic approaches to find workable solutions on behalf of society.

Peer research by, with, and for patients and communities is a significant next step to seeing that patients who want to learn the skills to conduct robust research and the researchers who are interested in using peer research now have access to a science of engagement replete with historical foundations, best practices, a growing literature, adapted theory and new theoretical proposals, and ethical frameworks and practices. It is written to speak directly to academics, researchers, and health professionals. As it was being written, I asked patients and students to read it, and they decided it was written for them as well. This confirmed the growing realization that peer research as part of a science of engagement needs to be accessible and understandable for anyone interested in emancipatory outcomes.

It relates directly to existing responsible research and innovation (RRI), open innovation in science (OIS) research teams, personal health research, and patient-led research roles, which are poised to move the change indicator in health from patient perspectives. Movements such as citizen science and Ashoka changemaking, along with established participatory action research (PAR) and community-based participatory research (CBPR) will hopefully find a science to support their efforts to democratize science. Emancipation increases responsible and relevant outcomes that lead to focused, nimble, and creative innovation in response to healthcare reform and dramatic paradigm shifts in health and healthcare.

While most methods included are qualitative in nature, they also work well in partnership with quantitative and evaluative methods. Links are provided to extend information about methods for group discussion and teaching purposes. Provincial and national patient groups, charities with patient engagement partners, groups of citizens who advise, and healthcare, along with Patient Advisors Networks (https://www.patientadvisors.ca/) who are interested in peer research, might use this chapter to explore the potential to promote peer research as part of their advising and partnership roles in health research. The format is designed to inform grant writing and co-design while incorporating engagement methods into existing teaching and research agendas and teams.

Professionally trained researchers and students who identify as a patient or person with lived experience (PWLE) may find this chapter particularly useful in their personal research or in training patients as collaborators in their research. Teams of health researchers may be interested in sponsoring or supporting patients to become trained peer researchers through existing community-based or patient-engaged research training programs and courses such as Wellesley Institute in Toronto and the Patient and Community Engagement Research certificate at the University of Calgary.

This chapter extends the current health research landscape and the descriptions of field work, interviewing, questionnaires, focus groups, and narrative research that are included in the companion book, *Grey Matters: A Guide to Collaborative Research with Seniors* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/). Also included is a section outlining how researchers and community groups might develop methods to address questions that are important to them and to provide input into developing health research courses and new community-based health options.

Characteristics of Peer Research

One can understand why people are initially puzzled by the concept of patients trained to conduct research. The power imbalances in health are protected by patients and communities who fear loss of their healthcare providers if they question their care. Peer research is not about challenging existing research or care but reinforces the wisdom of patients in explaining concerns from a unique patient perspective that leads to suggestions for action. In doing so, it provides a competent patient research voice about general practices and policies. Patients are ready to be part of improving healthcare and ensuring healthcare sustainability and are ready to advocate for and use their experience and expertise to become involved. It is important, therefore, to look at the common characteristics of peer and patient-led research.

To ensure patient research reliability, the methods included here were tested and modified as part of research projects and grants, with community and health system programs, students, and as part of professional workshops and presentations. This includes the *Grey Matters* publication of research methods and over 85 co-designed research grants and contracts. The methods here represent the scope of methods that become part of a blended methodology in the final chapter of this book. Here we focus on emancipatory methods that can be used in a wide range of research, including qualitative, quantitative, and action methods to inform both theory and action.

We thank especially the researchers and mentors who were early adopters in both *Grey Matters* and PaCER and were willing to try new methods to overcome challenges of engaging patients in research. It seems appropriate to begin this chapter with an example of peer research that captures the character of peer and community research. This is a community-based peer project titled "Understanding Advanced Care Planning Within the South Asian Community."

Four trained PaCER researchers from South Asian countries were contracted by an advanced care planning (ACP) grant to identify the readiness of South Asian communities to become part of an ACP initiative with Alberta Health Services (AHS). Each PaCER was from a different faith community, and all were women. As women, they conducted a women's focus group to identify the obstacles and opportunities for conducting this research. The peer researchers, the project principal investigator, and PaCER academics then met to discuss the need for a culturally appropriate data collection strategy for families and for the researchers within the South Asian communities.

We decided that any research involving end-of-life care should be done within families because the traditions surrounding death were generally led by the head of the family and each family member would also want to be involved.

A modified family research method was created to meet cultural protocols. The recruitment of families included a careful description of the ACP process and how the research method would meet cultural and language needs.

Each research event involved two peer researchers—one in traditional dress, the other in western dress. They met the family in their home and brought along tea and treats. The lead researcher (the one from the same faith community) outlined the process with the family, asking if everyone felt comfortable and, in the process, introduced herself and why she and her family felt that advanced care planning was important—a personal family story.

Adaptations were negotiated, if needed. Once the head of house had negotiated changes and set out how all members would have a chance to speak, there was a narrative conversation about the concept of ACP. Confusion and conflict with traditions were also discussed. All members—from grandparents to children—contributed. Other methods were not needed, as the data from families in all four faith traditions created very detailed discussions about family goals, the process of dying, and advanced care planning from all generations present.

The results were compiled and analyzed after each family gathering and shared with the team to plan next steps. The PaCER academic staff and peer researchers met regularly to provide support and discuss any ethical or methodological findings. As we neared the REFLECT consultation, it became clear that the topic had generated a great deal of interest in the community and a radio invitation was issued for a feast and a chance to be involved in the research findings.

The morning session consisted of the peer researchers and co-researchers who had participated in the research to discuss the research findings and plan for the afternoon session. The noon feast included faith-based and community leaders, community members, and health providers, along with the sponsors. In the afternoon, the results from the group sessions in the morning were presented to the group, with active discussion and answering the main questions.

Highlights included a leader in the community who spoke for many, indicated his appreciation for the chance to be involved. He suggested that if AHS wanted an advanced care plan done, why not leave it at the doctor's office on a computer that they could fill out and update as needed. An Elder spoke quietly to say that she felt that everyone was familiar with computers and they could discuss it amongst themselves. A doctor rose to say she could help and then a faith leader suggested that they could hold discussions after services to show their support.

The family method produced deep and rich information. The results contributed to the team's implementation plans and were published (Biondo et al., 2017, https://doi.org/10.1111/hex.12531/). The full report is available in PRISM (https://hdl.handle.net/1880/109933).

The following table introduces us to the basic characteristics of peer research to set the stage for this chapter that highlights how peer research differs from most general qualitative research.

Table 8.1 *Characteristics of Peer Research and More Traditional Research Methods*

Characteristic	Peer research	Qualitative research
Emancipatory	The overall goal is to build citizen capacity to engage in research about personal health and healthcare that makes a difference to patient roles in health care practice and planning.	To conduct research to understand and support patient vulnerabilities and to inform care providers and systems how best to support care and the interests of patients.
Salutogenic	To understand the salutogenic search for health and well-being to build capacity for resilience, confidence and well-being.	To understand the pathogenic nature of patient experience to understand how to address vulnerability and fallibility of illness and loss to improve outcomes.
Inductive / deductive	Inductive, iterative data collection, analysis, and interpretation with patients and communities. Each new step builds on and tests the accrued findings.	Deductive process—data collection completed and then analyzed and interpreted to test hypotheses. Increasing use of grounded theory for iterative data cycles.
Adaptable	Methods for data collection and analysis are adapted for in iterative cycles to ensure that methods engage population and topic appropriately and effectively.	Standard questions and data collection procedures for computer analysis. Semi structured interviews have some leeway.
Use of narrative	Narrative values and methods permeate all aspects of peer research from identifying the concern or topic to disseminating findings.	Selective use of narrative in data collection and some narrative analysis.
Data	In-vivo data of incidents are compared to form real life categories. In-vivo codes reinforces co design features of participation with co research participants.	Results of standardized questionnaires and interview questions are analysed at the end of the research to inform theory and practice.

Table 8.1 (*continued*)

Characteristic	Peer research	Qualitative research
Orientation	Action: What happened, what happened next, what could happen. Focus on a main concern of the population to find what action can be taken.	Descriptive: What was it like, how did you feel? Using thematic analysis to describe common categories of experience.
Group research	Open, extended conversations, small working groups and focus groups. Methods encourage creativity and consensus.	Groups follow scripted questions and processes.
Participation from the lens of citizen science	Citizen scientists are supported to engage in data collection, analysis and are valued for their local and personal knowledge.	Participants engage in data collection and may include analysis and dissemination. Results of the study may be shared.

Emancipatory Stance

To call research emancipatory is to align the purpose and methods of research with a mandate to reduce obstacles that reduce patient and community capacity to flourish and, instead, increase the possibility of becoming key stakeholders in their own health and healthcare. Why is an emancipatory social science needed at this particular time? The simple answer is that emancipatory research provides a local and real-life way of addressing what are considered 'wicked problems' in healthcare. Wicked problems are social, cultural, or institutional problems that pose often insurmountable challenges to aging systems, as indicated in the following healthcare resources:

- "Wicked Problems and a 'Wicked' Solution" (Walls, 2018, https://doi.org/10.1186/s12992-018-0353-x)
- *CREATE WISDOM: Wicked Problems in Healthcare* (UI Health, n.d., https://uihealth.uic.edu/research-clinical-trials/create-wisdom/create-wisdom-wicked-problems-in-healthcare/)

Peer and community research is pragmatic and focused on real-life, local health problems that are of concern to a specific population and to conduct research at the local level that provides opportunities to tackle wicked problems such as systemic racism and discrimination, obesity, and environmental toxins in management contexts. Emancipation has been supported by computerized

medical information platforms and patient portals that enable patients to collect and analyze their own data and share data with others. Online patient portals also develop connections and networks of patients who share common concerns and open new channels for patient-informed and supported research such as Patients Like Me (https://www.patientslikeme.com), where patients have become active in drawing attention to problems in the medical grey zone of 'no known medical cause or cure' (for example, see Callard & Perego, 2021, https://doi.org/10.1016/j.socscimed.2020.113426). 'My Data, Our Health' personal health networks are becoming popular in countries that support citizen science, where patients share and discuss their personal research about their health challenges.

Zamplo is a trend-setting breakthrough that fosters patient emancipation as a person-centred connected health platform, which "is designed to place the person at the centre while remotely capturing patient-reported outcomes and wearable data to provide valuable real-world insights into treatment efficacy and patient experiences. It helps identify adverse events, provides patients support, and empowers individuals to manage their care themselves" (Zamplo, n.d., https://www.zamplo.org/) It will empower people with the resources, knowledge and tools needed to understand their health information. Individuals can connect meaningfully with the wisdom of a global health community by sharing and working with caregivers, peers, patient advocates, researchers and health professionals to make the best possible decisions based on individual goals.

Salutogenic

Patients seldom realize that their experience with health problems and health systems is, in fact, knowledge that grows as they face the stressors associated with ill health and seeking wellness. This knowledge encourages interactions with health professionals and health systems. Salutogenesis is the study of the process of managing stressors by using and building personal, program, and system resources and resilience skills that includes cognitive skills that build confidence that stressors can be challenged and managed, and that it is worthwhile making an effort to face health-related challenges. It is asset based and a metric for ensuring that explanations lead to potential solutions. This contrasts with problem-focused pathogenesis that is the dominant discourse in health research. As technology influences our human bodies, salutogenesis will become even more essential if patients are to become active in technology development and implementation.

Inductive Approaches

Most health research is done within deductive research methodologies that test a research question by collecting data using a consistent method. When all data is collected, it is analyzed, often with computer analysis to confirm (or not) the hypotheses. Results are related to the original question.

Inductive approaches are common in emancipatory research, participatory action research, grounded theory research, and peer research, which use iterative cycles of data collection to gradually move closer to a best solution to a main concern of a local population. Researchers have more flexibility to test ideas with new co-researchers or in using forms of data collection based on the information found in the data. This is important in engaging patients because it provides a flexible, simple process to ensure engagement of groups by tailoring data collection methods to the needs and culture of diverse populations. Every time data is collected, it is analyzed by asking questions such as: What is happening here? What caused this to happen? What was the outcome? What should we study next (planning)? Inductive methods lead to rich interpretation in a short period of time because data collection and analysis is focused. This also means that research needs fewer participants and is less costly.

Inclusive

Peer research relies on the ability to reach out to populations that are not being heard because they have either given up or, more likely, because they are considered outside of the scope of standardized studies. For example, research with young people with sport-related concussions was difficult because so many people felt that they were responsible for the injured youth and tried to protect them from taking part in a study that might prove stressful. Indigenous focus groups were conducted with ceremony. Women researchers conducting research in Muslim communities required careful planning and adherence to gendered relationships. The need for peer research training will increase as we address the need to create bridges between marginalized populations and mainstream research. Inductive research is essential in laying the foundation for a flexible and adaptable research methodology of the future.

As peer research is adopted by innovation and social enterprise teams, adaptation, especially in the prototype development and testing stage, will be essential. Good design thinking is about learning about the potential diversity and being able to adapt to new populations.

Narrative

Stories are hardwired into the human brain to understand the problems of the past and dream stories of better futures. Narratives of change are becoming more popular in emancipatory research and implementation science. The use of a consistent story template helps peer researchers and participant co-researchers see stories as a legitimate form of data and knowledge as they evolve throughout the research cycle from a common concern, understanding why problems exist and how they work to open the door to narrative futures and forecasting solutions. Design thinking also uses story formats throughout to produce rich and flexible data focused on processes that solve problems.

The use of a story template helps peer researchers and participant co-researchers see stories as a legitimate form of data and knowledge that can be interrogated using standard narrative properties such as 'what is happening,' 'why now,' and 'then what' to understand how problems work in order to find potential solutions. Finally, stories, used as part of innovation and marketing research, shows that implementation strategies that include a vision conveyed through stories have maximum impact and increase uptake (Davidson, 2017, https://doi.org/10.1057/palcomms.2017.93).

In Vivo Data and Coding

The co-researched social innovation study (Chapter 2) faced the so-called glass ceiling of analysis when I used disciplinary concepts, language, and theories when coding data. The co-researchers felt sidelined because they did not share my academic language or culture. When we used the titles of stories as category names, we were able to re-engage in shared analysis. I realized that categorizing data held insidious assumptions that separated participants from academics, and I used grounded theory to find ways around this chasm between conceptual and real-life analysis. Step by step, study by study, throughout *Grey Matters* and PaCER we studied alternatives to test new approaches that could compensate for this lack of academic conceptualizing using discipline-focused theory. Community-based participatory research (CBPR) and participatory action research (PAR) use plain, in vivo language of everyday life to contextualize experience that reflects local culture and organizational structures. The language of peer research may not be conceptual from a disciplinary or theoretical foundation, but it does lead to deep, action-oriented categories of real-life experience. The following titles of peer research are examples of in vivo theories:

- 'Losing our stories,' that speaks to how medical language takes over during mental health crises

- 'Out in the cold without a clue,' after asking for physician help with lower-back pain
- 'Hiding undiagnosed arthritic pain'

Grey Matters and PaCER have found that the use of stories and plain language has been well received when publishing in professional journals. Peer research data has been re-analyzed by professional and academic researchers who use different languages but come to similar results.

Action Orientation

An action orientation is the hallmark of emancipatory social science of social problems in order to inform collective action. Through 40 years conducting and teaching about emancipatory research, I found the common question of participants was, 'Will this make a difference?' Participatory and action research was, for a long time, considered non-academic because the research addressed population concerns to explain, resolve, or reframe the concern. I encountered this skepticism from my PhD committee and even from colleagues who felt that action research was not objective because there was a 'political' goal.

However, the engagement strategy of PaCER—SET-COLLECT-REFLECT-INNOVATE—caught the imagination of the research community in Calgary. In team meetings, people seemed comfortable with the simplicity and pragmatism of a research strategy that consulted with citizens about the main concern or topic in order to co-design the research proposal (SET); engaged citizens in collecting and analyzing data (COLLECT); and brought the co-design team together to consider the best solution to address the main concern (REFLECT).

Group Focused

Group research was first proposed by seniors in the *Grey Matters* Catalyst grant. They wanted to create a focus group method that provided time to understand the topic, share stories and discuss common concerns. The resulting method takes more time and promotes crosstalk while creating shared meaning. These group sessions create common goals and ownership of the findings. It is perhaps the most effective peer method, producing not only data but shared meaning informed by in-depth collective stories that produce not only explanations of the main concern but the best and most feasible solutions.

Little did we realize that the magic of working in groups would unleash the power of improvisation. As groups shared stories about the present and the past, the interaction sparked new aspirational stories of change, foresight, and solutions. It is doubtful that improvisation exists without open discussion among diverse participants. These groups seemed to rely on the freedom and

crosstalk that builds trust and a common mission to make meaning of diverse experiences.

Group research is used to set priorities, collect a broad range of stories to inform the development of categories, reflect, and contribute to findings that suggest actions based on the findings. The SET consultation team captures the energy of connecting with the community to weigh options and choose their focus and the methods for the study and prepare them to engage in the research. COLLECT groups provide a rapid way to collect, analyze and plan next steps using group formats to reach diverse groups and perspectives. This is especially useful with small online groups. REFLECT re-engages the SET team to respond to findings, next steps, and action.

Participation from a Lens of Co-creation

The principles and relationships of participatory action research reinforce co-creation. Today, the terminology for engagement revolves around a number of 'co's, which compete for engagement space: co-creation, co-design, co-production, co-research. The following is a short summary of these definitions, with a summary of their use and those they engage with.

Co-creation appeared first and with a long history in innovation through design thinking. It grew from the early days of capitalism, when companies were looking for new products to entice consumers to buy. Customers and inventors were welcomed and encouraged to 'co-create' new products and services. The field of design thinking grew rapidly, and professional innovators moved quickly to take the lead. These include using social media, online communities, workshops, discussion groups, or in-depth interviews. Verleye's (2015, https://doi.org/10.1108/JOSM-09-2014-0254) research on the co-creation experience clarifies not only the history and practice of co-creation, but the motivations of customers and inventors engaged in designing products and services.

Peer research emancipation is co-creation with patients and communities who are co-researchers throughout the research process, from co-design through to analyzing data and finding ways to understand common concerns in order to co-create solutions and co-design implementation strategies.

Choosing Models of Participation for Citizen Science and Peer Research

In concluding this first section, we return to the levels of citizen science to describe the range of co-research related to the engagement of patients and communities in research. The basic approach is simple. Academics, mostly in the natural and environmental sciences, recruit citizens to collect data, analyze

data, or even conduct research. Many of the projects are ongoing and become collaborations that are networks of researchers and citizen scientists enhancing and extending the reach and relevance of their research.

In the introduction to Section 2, there is a comprehensive table outlining the five levels of the four most common citizen science approaches. It also includes the International Association of Public Participation (IAP2), which is a commonly used guide to engagement in governance and academic projects. The following is a summary of levels of engagement in citizen science that may help researchers identify the level of engagement they aspire to.

People involved in all forms of collaborative research feel they are part of it, commit to using the information, and support uptake. In the future, the preparation to become a co-research participant might include some basic online stories and the use of peer research reports. Co-researchers are motivated to become part of dissemination, implementation, and uptake.

Options Related to Peer Research and Citizen Science

This is an extensive collection of engagement methods following using the peer research engagement strategy.

- Co-design or SET that identifies the topic of the research from a patient perspective.
- Collecting data or COLLECT using interviewing, group research, field work and participant observation, and mining unstructured public data.
- Data management COLLECT.
- Data analysis that includes content and thematic analysis, narrative analysis, discourse. and framework analysis COLLECT.
- Interpretation using the categories above to connect to levels of theory and implementation REFLECT.

Co-design or SET

SET is the equivalent of the open coding in classical grounded theory that takes place in academic research prior to the ethics proposal. It sets the focus of the project within the context of the systems, politics, and values that impact the patient experience from their perspective. SET can be done by a trained patient researcher, a small team of patient advisors supported by a patient researcher, or an academic lead familiar with peer research who supports patients and community members. The goal is to collect and categorize a number of potential

research ideas that reflect the main concerns of patients or communities as an informal consultation. Some examples include the following:

- Consultation with experienced patients and community members through informal consultations in person or online.
- Online chat groups of all kinds to identify the concerns of the population within the topic of the research.
- Websites related to the general topic to identify program goals and gather consumer comments.
- Grey literature related to political, policy, advocacy groups.
- Practice protocols related to the topic.
- Reading and analyzing patient experience articles from open access journals.

Depending on the resources available and the time, choose from the above options. Keep the information about options for research using a simple story template, so that everyone is consistent in presenting topics of concern. When you have a range of concern options identified, write each on a poster that can be shared in person or online. If you are working as part of a research team, share the posters with them ahead of time.

A SET co-design team of patients and citizens meets to discuss and prioritize the options. The team can be drawn from your consultations or from an independent collection of patients and community members. This in-person or online group discusses the categories, weighing not only what is most important but also what is feasible and impactful. Once one or two concerns are identified, they are prepared for the team (the grant development team or early-stage research team). The report includes politics related to recruitment, advocacy, and community inclusions; the ethics related to engagement and equity, diversity, and inclusion; and suggestions related to methods. This is then discussed and included as part of the grant or implementation plan.

Collecting Data

The specific methods for collecting data are presented separately, although in peer research, data collection is combined with analysis because of the links to classical grounded theory iterative cycles. Iterative data collection is a cycle of data collection, analysis, memoing, and shared analysis, but for this discussion of qualitative methods for peer research, the elements of the cycles are separated.

Table 8.2 describes the four basic ways to collect data in peer research: individual interviews, group research, field work, and mining public and unstructured data. This figure summarizes the data sources, the use of stories, and how to track data collected using basic field notes. This is done to lead into the next section that locates and describes these methods within the engagement strategies.

Table 8.2 *Methods and Purpose of a Peer Research Engagement Strategy*

4 WAYS TO COLLECT DATA IN RESEARCH				
	Individual interviews	**Groups**	**Community-level field work**	**Public data**
Definition	Open interviews that invite stories of experience	Sharing experiences Creating common experiences and strategies	Observing interactions and actions within social situations Visiting people and noting community resources	Online searching and analysis wof publicly available data *(not subject to ethics restriction)*
Data sources	Audio tape Process recording Notes taken during interview	Flip chart notes Audio tape Process recording	Process recording Notes on observations Notes about conversations	Program descriptions Chat groups Policy
Data units	Words, phrases or sentences, that capture action or incidents, stories	Flip chart notes of incidents (what happened) Stories	Incidents as actions, behaviours, interactions, environment details Can be stories	Analysis of descriptions and data provided online
Stories as unit of analysis	Notes can be taken within a story template Can listen to audio tape and transcribe segments	Note individual stories around emerging common category or theme	Observations can be compared, told and recorded into a story format	User comments are stories, as are slogans, goals of programs, policies, and role descriptions

Table 8.2 (*continued*)

	Individual interviews	Groups	Community-level field work	Public data
Field notes as data	Notes taken to capture the nature and findings of the interview	Notes taken capturing the incidents that can be combined as group stories	Notes describe the social environmental, interactions and outcomes	Online data is data Discourse analysis can be used to identify power differentials

The next sections follow up with specific details about the data collection methods summarized above.

Interviewing

The initial study of interviewing for peer research took place with seniors who were taught open-ended, semi-structured, and standardized questionnaires. While seniors felt secure with structured and standardized interviews, they were disappointed with the results that were difficult to apply to their research with partner agencies and were difficult to interpret beyond counting the number of responses. The scope provided by open interviewing was more difficult to analyze but provided useful information that could be applied to their research.

Citizen science interviews often employ structured or semi-structured interviews that ensure that the citizen scientist collects the data needed for the academic research protocol. In this situation the data is collected in ways that allow for computer input and analysis. Even formal interviewing requires training in being able to engage patients and communities in the interviews. For more information on types of standard interviews that have been developed by seniors refer to the "Interviews and Questionnaires" chapter of *Grey Matters* (Marlett & Emes, 2010, https://prism.ucalgary.ca/server/api/core/bitstreams/b7ccdd45-80bd-467f-9f1e-d610823efd22/content).

Peer research interviews are more likely to be open, narrative conversations about specific experiences. A peer researcher uses their own personal stories to enable the participant to feel comfortable sharing their personal stories when it is appropriate. This is difficult for an academic to do because they seldom share life experiences with participants. In peer interviews, participants are prepared ahead of time so that they know the topic and that the topic was chosen by patients. The peer researcher generally has personal experience with the topic of concern. The purpose is to collect stories about what happened to them, and what could or should have happened.

You begin with an open and curious stance, inviting the participant to share their experience of the topic or main concern. You learn to listen to and capture stories by taking short notes of incidents that are story fragments about the topic. Incidents and story data are entered on the story templates during the interview, or you can wait to use the template later from notes or audio or video recordings.

The skill lies in creating a conversation of equals, interested in exploring experiences about a common concern or topic. You show interest in learning more about what happened and, as in a conversation, by prompting to hear more elements of the story. Stories lead to other stories on the topic and open up questions about what happened and why.

The nature of narrative conversations invites the telling of whole stories. Whole stories provide space for exploring meaning. The peer researcher is curious and interested, but avoids any reinforcements such as 'good,' 'oh my,' or 'me too.' These reinforcing statements lead the participant to think that they are answering an implied question, and they will search for the right answer or struggle to figure out what is expected in an answer. Learn to allow time for people to think. If you feel you need to provide support, a gentle prompt related to the story often works. This is where the story properties come in; you could ask 'who,' 'where,' and 'when' questions but try to avoid 'why' questions until the whole story is revealed.

The problem is that the use of standardized questions is often reinforced by ethics committees who see questions as a way of ensuring that research stays within safe boundaries. In medicine, patients are so socialized to being asked questions by professionals that the response is automatic, strong, and visceral: What is the right answer? What will happen if I don't answer correctly? Why is this being asked? What will happen if I answer the wrong way? How do I answer without criticizing my healthcare provider? Who will find out what I have said? These are not idle concerns. Patients spend a great deal of time and energy anticipating questions about their health and how to answer them, and they bring these expectations with them when they come to research. This is why the story format, while it may seem awkward in a health context, provides openings to explore explanations and solutions without triggering uncertainty about how to respond.

It is often useful to tell a story so that the co-researcher knows about the format and expectations.

At the end of a narrative interview, you celebrate the stories as important knowledge about the research topic by asking what the narrator has learned by telling the story and what they feel they have learned about themselves and the topic. In summary, a narrative interview is not a series of questions but an

integrated and meaningful conversation that leaves participants engaged and acknowledged.

Group Research as Data Collection

The group research method was created by seniors who were fed up with focus groups that lasted an hour and asked members to respond to set questions with no opportunity for crosstalk. The results were seldom shared and when they were, they didn't know how to respond. The full curriculum for groups can be found in *Grey Matters*, Chapter 5 and Appendices 4 and 5 (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/). The power of the group is also embedded in SET and REFLECT consultations that guide the choice of research topic at the beginning of the research and consolidating findings at the end to reinforce that peer research is guided by patients.

Group research is the magic ingredient in peer research. Groups ground engagement and consolidate a conversational sharing of stories to create common stories. Peer research aligns with JEDI principles of justice, equity, diversity, and inclusion. In particular, the diversity of peer research groups seems to foster common stories that are more powerful because of the diversity of experience. The following are examples of group research.

In a three-country study of women immigrants with suspected cancer, the SET and COLLECT group were conducted in Russian, Portuguese and Arabic languages, and when the stories of the three groups were combined after the REFLECT stage, the commonalities stunned us all. All women felt Canadian physicians were more clinical and less supportive, especially when it came to physical testing and conversing about feelings about cancer. The diversity reinforced a common immigrant discourse in spite of very different backgrounds and care experience.

Similarly, in an advanced care planning study in South Asian communities of Calgary, the initial data collection included a peer researcher from one of the four faith and ethnic communities and, as the results were discussed, the similarities led to powerful recommendations that were shared by all four traditions.

A final example is of Indigenous cancer prevention studies that included two treaty-based nations, an urban mixed Indigenous group and a Métis community. The data of each of the groups reflected their different cultures and traditions but each had similar concerns about the lack of cancer survival stories that led to hiding early cancer signs. The lack of stories of hope increased the devastation when patients were separated from their families for late-stage cancer treatments that reinforced the notion that cancer meant death.

As the use of JEDI becomes more ingrained in peer research, group research will become more involved in justice because the diverse groups will provide equity, diversity and inclusion examples of experience. Explanations of concerns and common solutions benefit from the ability to study a diversity of ideas that generate an almost improvisational energy during group sessions. The more diversity, the deeper the data possibilities. Group energy builds not only results but shared ownership of the stories. Some of the most exciting results have occurred when the groups work to reconcile differences. As the group negotiates a common story that reflects the diversity of the group, it generates space to explore new explanations and solutions.

The following identifies the data collection aspects of groups from *Grey Matters*. Many peer researchers like to work as a three-person team who take on the following duties.

- **Facilitation** is done 'sitting down' to be seen as a group member. Facilitation starts the conversation and supports and redirects conversation when the group stalls. This is not a leadership position—it follows participatory action research principles that state all group members are equal and bring differing but valued contributions. The facilitator might say nothing for an hour when the openness and respect for ideas and diversity is evident.
- **Flip charts** are created by the flip chart recorder, who stands up so that everyone can see as the data is recorded when the group is in person. The recorder records using a visible chat function when working online. Either way, the flip chart pages become the group data record. The flip chart person records conversation in small incident units. The names of contributing members are not included, unless the group requests that they be noted. The flip chart person is responsible for the integrity of the data, checking to make sure that the incident notes on the flip chart are accurate. This person also identifies when incident notes are turning into stories. These stories may be recorded on separate flip charts to allow groups to think in stories. The flip charts of stories are used for group analysis at the end of the day.
- The use of flip charts is more complex unless there is the ability to send data to each participant when a topic or story is completed. Each participant still has to scroll through the data instead of being able to see all the data at once.

- **Process recording** is done by a team member trained in recording what is happening in short incident notes. This is not a recording of content, but the nature of the conversation, ideas that resonate or separate the group, and the emotional connections that grow as part of the process. This provides the context and relationships within the group.

Groups are often involved in co-research analysis that informs important research decisions—SET: choosing the main concern or topic for the research; COLLECT: comparing categories to find the core category that explains the main concern; and REFLECT: confirming the findings and suggesting solutions and next steps. The afternoon ends with a summary and reflections on what they have learned about themselves and the topic, and what they think might be needed next and how they can help. The day ends with a short evaluation of the day and the process with invitations for next steps.

Focus groups create not only a consistent collaborative research environment but also motivation to continue to be involved in other peer research and often an interest in becoming a peer researcher.

Fieldwork and Participant Observation

Observing and taking notes is an essential skill, not only for fieldwork or ethnographic study, but because it highlights what the observer considers important to help unpack biases. These skills are essential for interviewing and group work, or any situation where information is collected by observers. Fieldwork is used at the SET stage of consultation with key informants and visits to community and clinical resources (Marlett & Emes, 2010, https://prism.ucalgary.ca/server/api/core/bitstreams/b7ccdd45-80bd-467f-9f1e-d610823efd22/content). The ability to observe and take short notes about possible concerns that might become research topics, ensures that those being observed don't feel that they are being researched. This is important because research per se must occur after ethics is approved.

In data collection, we focus on 'participant observation,' which typically means that one person participates and observes at the same time. In peer research, observation is taught in pairs so that they can share notes and discuss the impact of personal values on what people look for and record. The goal is to establish inter-rater reliability, which is achieved when observers are aware of their personal biases and expectations and can focus on what is happening instead of what they expect to happen. This takes time to achieve but is easier when one person observes and records as the event unfolds, and the other person participates in the event and records after the session. This allows the

participant and observer to compare their observations from two perspectives. This exercise teaches about research and the need to be open and not be drawn into looking at action through biased eyes.

This method was developed as part of a PaCER internship research project at Wellspring Calgary. The SET consultation identified that the best and least intrusive option for gathering data of classes and groups for cancer survivors was to observe activities and casual groups. The research team, whose members were from Wellspring, and the academic supervisor worked together to create a way for one person to observe and record while maintaining a discrete distance. The other person took part in the group and recorded their experience after the activity was completed. This is an example of adapting data collection methods to suit the nature of the community setting.

Participant observation is also the most difficult process to get approved in healthcare settings. Staff are often uneasy about patients watching healthcare being delivered. While it may be difficult to gain access, observations in clinical and community settings come with the expectation that the writeup of the observation is shared with the staff to discuss findings and to share the summary with any staff who are interested.

Shadowing doctors is often used to enable students to see first-hand the roles they aspire to. A similar process occurred when students in the PaCER program were able to act as research assistants in a peer research project in an intensive care unit (ICU). Their experience led them to choose to research about the transfer from the ICU to the step downward. Shadowing is an excellent way to study reactions in hospital or clinical settings, and sometimes the best way to achieve this is to arrange for a patient, who has permission, to observe their care and record what they experienced.

Mining Unstructured Public Data Sources and Artifacts

There is an explosion of publicly accessible information, personal beliefs, opinions, and experiences through the internet and related social media platforms. It opens new meaning to the grounded theory contention that 'all is data.' These new and widely available data sources are unorganized and require careful attention to ensure data quality, especially reliability. Data mining is not new in marketing, public opinion, and values research, and with more interest in citizen science, these new forms of data will become more a part of more formal co-design and research.

Some of the public sources of information include the following:

- Interactive news publications, customer generated online comments.
- Social media platforms such as Facebook, LinkedIn, Reddit, etc.
- Video streaming websites like YouTube and photo sharing platforms like Instagram and Flickr.
- Medical records and health chat rooms such as HealthfulChat (https://www.healthfulchat.org/), Patients Like Me (https://www.patientslikeme.com), Health Experiences (https://www.phc.ox.ac.uk/research/research-themes/patient-experience), and Health Talk (https://healthtalk.org), along with an increasing array of professionally led open chat discussions.
- Personal research platforms, such as My Data, Our Health in Holland, are opening new opportunities to access how patients understand the issues related to their health concerns. As these are translated, it will build opportunities to share personal health research results across countries.

These data sources require the use of peer researchers familiar with internet practices, because they have more expertise in assessing data quality, reliability, and soundness of online data. Accessing these data sources may also require the assistance of those familiar with the target online resources. Online resources may be a good place to begin co-design, because the use of media platforms for data collection is a growing field and it doesn't require ethics approval. The use of crowdsourcing has been used to access simple, low-tech, inexpensive solutions to fight COVID-19 (Ramamurti, 2020, https://hbr.org/2020/10/global-crowdsourcing-can-help-the-u-s-beat-the-pandemic). The use of online technology in citizen science is informing all levels of data from individual protein folding online competitions to artificial intelligence networks that are informing national COVID-19 planning teams. Clinical studies are adopting crowdsources to extend sample diversity and hard-to-reach populations.

Data Management

All data collected needs to be managed and protected. Table 8.3 is a short summary of some of the options that have been proven successful in peer research. Each management approach requires training and oversight to ensure that data is held in secure storage according to ethical standards. Each of the data management options have assets and obstacles in peer research and some adaptations are included.

Table 8.3 *Six Ways of Managing Data for Sorting and Categorizing*

Data	Asset	Obstacle	Adaptation
Audio and video recordings	A permanent record of the data collection event as a reference for all other data management tools	Privacy issues: These records must be secure at all times, which makes it difficult for teams to share the recorded data	Audio and video recordings can be held temporarily while transcripts or incident lists are being prepared Some sponsors request audio recordings, but this can prove dangerous as the participants can be recognized. Avoid it if possible Quotes can be accessed and depersonalized as needed
Full transcripts	Most qualitative research uses full transcripts for quotes Peer research tends not to use full transcripts, except during training to listen without bias	Time consuming Computer transcription needs careful editing Participants are often uncomfortable with full transcripts	Use audio and flip chart notes to take short notes and identify those areas most related to the topic Use full transcripts of sections that may be used for quotes
Speech rhythm transcripts	Connection to participant Fast and easy to transcribe Speech rhythm reinforces memory	Novel approach may be foreign to qualitative researchers	Speech transcripts often mirror incident notes in story transcripts Use as text backup of audio tapes
Short incident notes of 'what's happening' or 'what's it like'	Consistent format for all data collection methods Includes unstructured and social media data	Qualitative researchers may still require transcripts	Begin using short incident notes as part of SET focus groups to build competence in using short incident notes in other data collection methods

Table 8.3 (*continued*)

Data	Asset	Obstacle	Adaptation
Story template that includes the context of the research, the steps in the plot and the consequences of the story	Template can be used in all data collection Templates are used for both incident analysis and story analysis Provides common format for data management	Shifting templates as individual stories become group stories	Templates can be used during data collection Story templates can be used with participants when sharing stories and when analyzing stories at the end of COLLECT interviews
Framework templates	Each team member can enter their data directly from recordings into a case/concept framework template	The use of a framework may encourage quick analysis without consultation	When the basic framework is known, it helps identify options for co-design topics and main concerns

Whenever possible, students and new researchers should ensure that there are audio recordings of their work so that they can refer to them to relive their experiences, evaluate their style, and think about how to interview better. It also helps to learn, to listen, and record in short incident notes or story templates.

The speech transcript was introduced in Chapter 2 as a way of capturing the patient voice with the rhythm of speech. Also in Chapter 2, there are numerous examples of speech transcripts that produce a natural speech rhythm, which improves memory and connection. Reading speech transcripts produces a feeling of hearing the person tell the story. This method is useful in reports developed for patients and communities and has been accepted in peer reviewed journals. A short example of a speech transcript might be:

When I am in a new group

fear strikes

I tend to attach myself to someone who looks friendly

I can then follow their lead until I feel safe.

Short incident notes and stories are the preferred method of managing data in grounded theory research and other participatory and inductive research methods. They can be collected or produced on incident cards to increase the

ability to sort and compare incident notes during constant comparison. It is easy to take pictures of the cards in a category for data tracking. Notes can also be added on the back of cards. I have tried to do this using online organizers and would encourage their use if using cards seems low tech.

Narrative data collection using story templates can be produced during data collection from short notes or by listening to audio recordings. When seniors found it difficult to transcribe data or take short notes, they suggested using the story templates to manage data. It was easier to use the story templates, filling in the spaces as they listened to the tape repeatedly. It also has the benefit of identifying gaps in data collection. It is common that the storyteller misses important information that describes the initial context or in the consequence of the story. Many participants enjoy seeing the story being recorded on the templates as it takes shape, and have commented that it makes the story real to them and valued by the researcher.

The framework method for data management creates a structure at the beginning of data collection to enable researchers to enter their data quickly and compare entries to build analysis structures. There are computer software options to move through the stages from initial categorizations to final reporting. This framework research by Gale et al. (2013, https://doi.org/10.1186/1471-2288-13-117) is an excellent source of framework analysis in policy research.

As a tool in peer research, frameworks organize and manage data into a consistent matrix consisting of columns organized by basic themes that can be redefined. The rows represent cases in framework analysis. The cases are organized according to the structure of the research such as different researchers in a team, different disciplines in a team, programs according to focus, stage in treatment, funding formats, etc. The resulting matrix reflects the unique needs of the research.

Data Analysis

Data analysis is the process of taking data apart into pieces that can be questioned and sorted into similar categories, then recombining these pieces of data to capture new meaning about the topic. Constant comparison of incidents leads to coding or naming the categories that represent the collective meaning. In peer research, categories are named by the actions or descriptions of what is happening. Qualitative research in general is more descriptive of what the experience of the incident was like. Peer research analysis is encouraged to remain grounded in in vivo language and codes for categories to ensure that the research remains in a patient voice and captures patient experience.

Note that statistical analysis is not included in the list of peer research options, although there are computerized thematic analysis tools that are easy

to use that could be adopted by peer researchers. Scoping reviews are also not included, although McCarron et al. (2020, https://doi.org/10.1111/hex.13054) worked with three collaborating patients to conduct a scoping review of patient motivation for interviewing. There are several articles published with the patient collaborators relating to the possibilities of training patient colleagues to conduct a variety of research methods. Refer to Chapter 5 for more details.

Table 8.4 outlines the major data analysis techniques used in peer research. In raw data, the units chosen and the codes of potential categories all use the same language.

Table 8.4 *Analysis Methods Applicable to Peer Research*

Type	Focus	Example	Assets	Difficulties	Adaptations
Content and thematic analysis	Comparing data to sort into descriptive or emotion category codes	Challenges with food for patients with Inflammatory Bowel Disease	Descriptive data Many computer options available Variety of coding schemes	Academic traditions use theoretical codes that may not be meaningful to patients	When thematic analysis is used in peer research, real life codes can be used throughout
Classical grounded theory analysis	Identifying and explaining main concerns of populations Theory is generated directly from data.	Peer resources in community-based support programs	Rigorous, structured analysis	Focus on conceptual categories	Use of story as 'incident' or unit of analysis Use of in-vivo, real life codes for categories
Narrative	How people form and share meaning through stories.	Losing our stories when diagnosed in a mental health system.	Common unit of analysis for all data collection Properties of stories inform interpretation.	Not widely accepted in academic journals.	Common story template and analysis format makes it easy to teach and share ideas not related to research, per se.

Table 8.4 (*continued*)

Type	Focus	Example	Assets	Difficulties	Adaptations
Discourse and systems analysis	The study of language to find meaning and power in relationships and systems	Analysis of online program descriptions to identify the role of patients and their agency related to their health	Focus for systems analysis at all levels Easy to teach and access through social media	Can be threatening to systems	Use of analysis of language at all levels from policy to the patient/ provider interaction
Framework analysis	Organize and manage early findings of team members	Contrasts themes across specific programs in an organization	Rows (cases) and themes enable early and summative data to be analyzed quickly	Mostly used in descriptive categories and requires oversight to ensure common reporting	Excellent for shared analysis of peer research teams, where each member analyzes a theme

Content and Thematic Analysis

The majority of qualitative health research uses content and thematic computer analysis where data is sorted using pre-established category codes created by the researcher. Most current computer analyses allow for the emergence of other categories. Computer content analysis of social media has become popular in quantifying patterns and categories of values, preferences, and expectations. There is a broad range of content analysis software (solutions for public and unstructured text data in chats, comment sections, news, blogs, and social media platforms). One example is Intellspot (Valcheva, n.d., https://www.intellspot.com/content-analysis-software/).

Peer research methods for general qualitative studies have used content analysis but may be challenged by theoretical coding processes that require advanced academic training and experience.

Regardless of the process or the type of data, content or thematic analysis builds bridges between talk and meaning. Whether that meaning is presented in descriptions of experience, stories, strategies or new ways of doing things, the goal is to use data to confirm or uncover meaning.

Classical Grounded Theory Analysis

While classical grounded theory was the research method used during the innovation and incubations stages of peer research, Holton and Walsh's (2016)

book, *Classic Grounded Theory: Applications with Qualitative and Quantitative Data*, provided a modern take on classical grounded theory as a method that can be used with many research traditions. This book is recommended for those who have not used grounded theory previously because it is applicable across many disciplines and research traditions.

Classical grounded theory has been adopted widely as a part of qualitative research analysis to increase rigour and concept development. The analysis tools used most widely by qualitative researchers are iterative analysis cycles, open coding, and constant comparison of data. Iterative analysis not only ensures focus but also increases the potential for unplanned concepts and theory to emerge.

Classical grounded theory analysis consists of creating short incident notes from whatever data collection method is being used. Whatever the data, the first analysis question is: 'What is happening here?' A more traditional question, if you are focusing on early abstraction of concepts, would be: 'If this is my data, what am I studying?' Analysis exists as part of constant comparison of the incidents that lead to categories and eventually theory. These categories are named or coded according to the shared meanings of the incidents included in the sorted categories. If the new incidents don't find a home in any of the categories, a new category is created and named. Categories are expected to divide or combine through this process to refine their relevance to the main concern of the study. Throughout this process, the definition of the main concern or topic is being refined, and one category is selected that best explains the underlying structure of the main concern or topic.

The Holton and Walsh book was instrumental when combining classical grounded theory with participatory action research principles of the peer research's engagement strategy.

- SET: An open coding process that collects and categorizes concerns of a population. The analysis of open coding iterative cycles, as part of a classical grounded theory study, is done after ethics approval. More recently, in peer research, the mandate to empower citizens in the selection of the research topic opened opportunities to use open consultations with patients, community and clinical services, and online platforms to create categories of concerns prior to ethics and this has streamlined the identification of the topic of study as a common concern of the population involved.
- COLLECT: This includes iterative cycles devoted to collecting, analyzing, memoing, and planning next steps in the research process. This is done to focus on explaining the main concern

to find solutions. In peer research, the iterative cycle includes similar functions of collecting, analyzing, and memoing that are the functions of an individual peer researcher who analyzes their particular data collection events. However, the individual analyses are shared with a peer research team to combine and challenge emerging categories in order to plan the next cycle. This ensures both theoretical sensitivity and increased rigour that comes with interrogating emerging categories as a group.

- REFLECT: This includes interpretation and theory building. Theory is pragmatic, and it consists of a core category that best explains the main concern. This core category also coordinates other categories in finding solutions to the main concern. In peer research, the best choices are presented to a REFLECT focus group, which confirms or modifies the choices from the iterative data collection and analysis cycles. Selective coding identifies the core category. This enables patients to confirm the findings and to be involved in identifying solutions and options.

Grounded theory analysis is ideal in new areas of research, conflicted or confused social organizations, or in tracking social innovation, because it adapts easily to unexpected information. Grounded theory is particularly effective within organizations where the roles and relationships are the focus of study.

Narrative Analysis

Stories are the currency of communication, and they are the foundation of data analysis in peer research. Narrative focuses on the ways in which people create and use stories to interpret and explain daily life and world views. As such, narrative analysis includes a wide range of options, depending on the profession or discipline. Anthropology and ethnography gravitated early to use stories to capture knowledge about people, their culture, and adaptations. Sociology and nursing produced ways to analyze the content of stories, and psychology specialized in ways to understand how people form meaning in their lives through narratives. In general, narrative analysis helps make sense of past experience. It organizes our current experiences and uncovers the values, expectations, and structures that lead us to share stories with others to create common stories and narratives. Narratives of change and forecasting narratives focus on the anticipated futures that emerge from story analysis.

The narrative analysis as part of peer research is based on collecting data incidents that are analyzed initially using story templates. These templates organize data according to the context of the story, applying the questions about

story properties - the who, what, where, when and how - to probe for ways to categorize data. The steps, or plot of the story, provides the strategy, or expected process of the story. The consequence includes the expectations, outcomes and impact of the story. In addition to the story, a range of narrative functions are identified including metaphors, mottos and slogans, roles, and values.

The early analyst focuses on the apparent questions—the who, where, why and how—but as they gain confidence, they become attuned to the subtle nuances of individual difference and style. Narrative analysis aligns with grounded theory because both are looking for explanations of what is happening in the data. In narrative, the question 'what is happening here' leads naturally to the properties of the story: who was involved and what actions were in play. When asking how the story unfolds, we are looking at the dynamics of the movement that unpacks the power of using the story in analysis of the entire incident (why did this occur), flow (why did this happen next), the highs and lows. The individual elements of the story are also used to tease out the subtle actions, shifts in focus and meaning. The story invites the analyst to repeat—what is actually happening here and why? This iterative process leads to a main story or script that best describes the main concern of the research. It is also possible to use the main story to confirm related thematic analyses. The goal of the narrative is to provide real life data of actions in the past and propose actions for the future that are understandable to patients, healthcare professionals, the general public, and policy makers.

Discourse Analysis

Discourse analysis focuses on analyzing language, especially the language of power and the powerful. Direct access to speech acts as data that identify pronouns, verbs, metaphors, and role descriptions. There is an example of discourse analysis of stories in autobiographies in the Resources section of this chapter. Discourse has been particularly useful in emancipatory research because language and the structures of language uncover both sources and impacts of systemic discrimination and therefore study sources of power and wealth or privilege that can be used to confront power.

The use of JEDI principles provides a framework for classifying language used to promote systemic power tropes that produce access to justice, equity, diversity, and inclusion within the study of policy and practice in health systems. Discourse analysis of systemic discrimination using these principles is now a viable option because of public access to social media documents, program and policy statements, and advertising. Critical theory research uses discourse analysis to detect power imbalance and systemic obstacles. Discourse analysis also identifies personal roles in organizations, professional relationships, and

business practices that protect power through structures and policy that can be employed as a secondary analysis after the initial analysis is complete.

Framework Analysis

Framework analysis provides an early stage of analysis throughout, regardless of research methods used. The engagement stages highlight the use of framework analysis in peer research.

- SET: Co-design team of patient researchers can enter preliminary data about the potential topics or problems for research. These can be entered by the team members as possible topics or social problems for co-design. This framework matrix could replace the current use of posters of possible topics for research for a SET co-design team to prioritize. The matrix could also be used in rating each topic or problem during the SET focus group.
- COLLECT: During data analysis, the framework template could initially be used to record data at each iteration, and then it could be used to redefine cells according to the level of theme and subthemes. In action research, the template could be used to identify various ways that data inform or explain the social problem of the research.
- REFLECT: The co-design team of patient consultants could use a framework template to summarize categories related to the topic or to portray the explanation of the main concern, based on the core category and properties such as sequence, actors, location, and funding.

It would be interesting to test the acceptability of framework analysis beyond the ability to organize and present data and findings. While it is effective in identifying similarities and differences in an easy-to-understand format for shared discussions, the eventual quality of the interpretation or theory is yet to be tested.

Framework analysis increases the scope of analysis. Tremblay et al. (2017, https://doi.org/10.1002/ajcp.12142) introduce a number of frameworks in community participatory research, a framework analysis process using in vivo codes in a study of patient experience in emergency care. The article provides a step-by-step approach to framework analysis although it is not called a formal framework analysis because the actors are not included.

The following is a peer research example of a similar process of abstraction. Note that peer research is generally simplified to include fewer steps.

[Direct quote—transcribed with natural breaks with in vivo incidents.]

As I noticed changes in the way people reacted to me,

it became important to be more like everyone else

Being normal is impossible

It always leaves me feeling alone

I always expect to fail.

Incident

I feel alone and expect to fail when I try to be normal

In Vivo Category Codes

I don't belong

Trying to fit in

Expecting to fail

Interpretation

At this stage, interpretation options tend to blend. Interpretation is the act of explaining, reframing or otherwise understanding the meaning of a main concern, phenomenon, or practice. It uncovers the underlying structures in what people do and say. The term 'interpretation' exists at the level of categories, pragmatic, explanatory, and conceptual theory. As such, it includes qualitative interpretation of themes and classical grounded theory that includes explanations of the concern and potential solutions. Because inductive analysis consists of constant comparison and memoing, interpretation occurs throughout the peer research process when using grounded theory as part of a blended methodology.

Interpretation is practised by peer researchers and participant co-researchers at the end of each data event, by individual peer researchers, by the peer research team and by the REFLECT team that consists of peer researchers and consultants from SET or COLLECT phases.

Memoing is the act of documenting what you are noticing, the patterns and questions that emerge. A memoing trail of meaning becomes the thread of interpretation as you develop a sensitivity to ideas that are emerging. In peer research, memoing is considered a personal and private chance to create your own conceptualizing style. This personal memoing occurs prior to sharing analysis with the peer research team so that each person is prepared and more confident in planning next steps.

I have noticed that, while not an official characteristic of peer research, inductive research itself develops a finely tuned sense of pragmatic theory. While becoming immersed in the data and analysis, peer researchers become tuned to underlying concepts and potential directions for sampling and adapting methods. The following is an example of a team approach to promote individual conceptualizing.

A large team of student interns held a day-long focus group, and each person analyzed a portion of the flip charts. Each intern wrote memos about the categories that were emerging and what interested them most. While personal memoing is considered a personal and private process in grounded theory, it prepares each intern to take part in shared analysis.

During shared analysis, the first intern presented a category they had identified from a sample of incidents and why the category was of interest to them. The intern then facilitated a group discussion about the category and invited other team members to contribute data to that category. Each team member had a chance to present a new category or a change to an existing category. This version of shared analysis provides a learning process for personal conceptualizing and shared decision-making. It is made possible as part of peer research because of the use of in vivo and real-life coding that focuses on what is happening instead of relying on emerging academic concepts.

Once there is an initial plan for how the categories work with the main concern or topic, a REFLECT focus group is convened. This consultation includes mainly patients and community members who were involved in the SET research. They work with the findings from a patient perspective. They challenge categories and their relationship to find a coherent presentation that explains, resolves or describes the findings. The REFLECT group then discusses the potential impact and suggestions for implementation or innovation. These lead to discussions about how to present the findings, potential audiences, and

opportunities to try out the findings. The session ends with an evaluation of the research process.

Because interpretation is not a separate process, we come back to the analysis frameworks that were used throughout to describe the process and expected outcomes.

Thematic Interpretation

The final stage of thematic analysis is a process of consolidating main themes and the hierarchies of subthemes. Quotes are generally incorporated into the structure to capture patient voices. This often leads to discussion of each thematic hierarchy.

Grounded Theory Interpretation

Grounded theory as action-based research arrives at the end stage as part of iterative cycles that support analysis and memoing of the emerging explanations of the main concern and resolution of that concern. The focus on the main concern and individual memoing that supports shared analysis builds momentum toward a consolidated picture of what is happening to create and sustain the main concern. The essence is a simple and actionable pattern that leads to specific recommendations for action backed by evidence.

Narrative Interpretation

Narrative interpretation provides a way of conceptualizing findings within a story framework. Because narrative supports all forms of data collection and analysis, it can augment any stage of the interpretation processes. One of the interpretation tools identified during narrative analysis of autobiographies by undergraduate and graduate students who used story templates throughout their class research is presented below.

Autobiographies were eventually analyzed using an abstracted script template that captures the context, plot, and consequence of a category. The context is abstracted using the property of 'when,' which identifies the setting from the person's perspective, and as such it begins the template with the 'I' pronoun. The plot is reduced to the fundamental action that describes the property of 'how.' The consequence captures personal life story changes, beginning with the 'and then' property.

[Direct quote—transcribed with natural breaks.]

I noticed changes in the way people reacted to me

It became important to be more like everyone else

Being normal is impossible

Eventually it left me feeling alone

Always expecting to fail

Potential Script or Interpretation

When people notice the change in my condition

I try to fit in

And when it doesn't work, I feel more alone and a failure

The benefit of these simple scripts is that they are easily understood and tracked by researchers and participants during and after research. Scripts can be combined and structured into a final interpretive scheme. Action scripts also focus recommendations for prototype testing and implementation. This method of interpretation is expanded in Chapter 10: Standpoint Theory.

Discourse Interpretation

Discourse analysis results from the investigation of language to uncover sources and supports of entrenched power. It uncovers pragmatic and systemic theory about the influence of power at the level of relationships, organizations, or society. This opens a power-based debate about why actions and relationships occur the way they do. A power-based interpretation can be applied at all stages of analysis and interpretation where you are searching for agency, both internal and external, to understand how actions happen and why people take up the roles they do. In Section 3, discourse analysis is used in Chapter 10 to locate the sources of power that patients experience within the health systems they use.

Framework Interpretation

Like discourse analysis, framework analysis is a secondary tool that opens avenues for discussing interpretations.

Quality Indicators of Peer Research Partnership

Measuring Quality in Peer Research

Quality indicators can be considered from a number of perspectives. The peer research method adopted a classical grounded theory analysis to provide a consistent, focused, and robust method of analysis and interpretation. The key to grounded theory quality lies in the process of iterative data collection and analysis through constant comparison, memoing, and planning next steps. This is the benefit of grounded theory standards that ensure that measuring and testing theory is built into the research fabric.

The quality indicators for grounded theory research include four practical criteria. A fifth category, engagement, is added for peer research.

- **Fit**: The final theory fits with the original main concern and the data.
- **Work**: The theory does what it is intended to do; in other words, it works to inform the underlying structure of what people do and say.
- **Relevant**: It is useful for those who share the same concern; it makes sense.
- **Modifiability**: The theory can be applied and modified for different populations and different concerns.
- **Engagement**: This category was added for peer and community research to identify how patients and community members were engaged in the research and how the results can be used in engaging other groups and communities.

The following criteria were developed at the end of the *Grey Matters* project to formalize how peer research was different from qualitative research:

- **Real-life language:** All communications, including proposals, interactions, meetings with stakeholders and media, research methods, and protocols, reports, and articles use language that is understood by all. Concepts may become abstracted but retain real-life experience examples.
- **Representation**: The various voices in your project are clearly recognized and documented. Representation is a negotiated process. The methods for achieving partnership at each stage of the research—from creating the research agenda to presenting findings—are negotiated through a process of mutual agreement (cf. Chapter 3).

- **Relevance**: The process and results should signal a change in the practices of research. Begin by reviewing the following principles of collaborative research with each person who joins your team. These set the expectations of how all researchers and participants will be included in the process:
    - **Equal but different:** The thoughts and beliefs of all participants about the shared questions and issues are equally valid. Everyone from the grant holders, project coordinators, peer researchers, co-research participants, and volunteers need to accept that each person will have a say.
    - **Trust:** Trust is hard to earn and is quickly lost. Actively acknowledging the contributions of participants leads to greater understanding and an openness to hear and learn from the voice of others.
    - **Shared power:** Nobody decides for somebody else. Sharing power starts with the expectation to listen and the freedom to express opinion. Each person learns from others and grows in their own confidence and capacity. The team lead and committees need to ensure that there is a consensus process in place for meetings and a process to make decisions between meetings. This requires a strong team lead that summarizes information and data for discussion, sets meetings, writes minutes and emails, and maintains open logs of progress. If the participants are going to own the results, they must feel they own the process.
    - **Shared work:** To share expertise, there needs to be a willingness to use common language, and model and mentor unfamiliar activities. Learning to share requires time for reflection on the process and joint ownership of successes and failures. Working together includes the glamorous tasks of planning and committee work, but also the tasks of clearing up, making tea, and taking the heat for missing deadlines. It may be just as hard for an academic to learn to chat with a potential participant over tea as it is for a senior to analyze data. Neither task is exclusive in collaborative research.

Are We Doing It Right or Is It Any Good?

We end this long and detailed chapter with a comment made by JW from the *Grey Matters* project, who summarized the thoughts of her research team of

seniors: "It may be easy to learn how to do the research but then, how do we know if we are doing it right or if it is any good? These words resonate with most research innovation" (Marlett & Emes, 2010, p. 25).

JW has a good point—wanting to do research isn't enough; it is necessary to know the standards used to judge good research, so that there is confidence in the quality of the work. The standards for judging quantitative or experimental research (experiments with numbers) are widely accepted. Reliability in quantitative research means that the findings can be replicated by others who use the same procedures.

The following are commonly accepted standards for qualitative research. The criteria of quality in grounded theory includes clear measures of clear links between the concern, data, and findings (fit). Does the theory work for the reader, is it relevant or make sense to people with similar experience, and is it flexible enough to be useful for similar concerns or problems?

Credibility

Are the results believable from the perspective of the participants in the research? Would a patient or a member of a marginalized group who was cruising the internet have faith in what you are presenting? This includes faith in the question, the methods, and the findings. This is where peer research has the edge over most academic researchers. If the research is designed and conducted by patients, the results should speak to patients.

When patient's use research done by other patients, they will likely be surprised that peer research exists, but as they respond to the concern identified, the explanation of the concern, and the suggested actions to make a difference in their language, they are likely to resonate with the process used and be intrigued by the results. Because peer research uses the pronoun 'we' in articles, researchers are building a relationship not only with the patient participants but with other patients who are concerned about similar problems.

Transferability

When a researcher talks about findings or writes an article, they need to think carefully about how other people or programs might translate the findings to their situation. To accomplish transferability, the researcher starts by carefully describing the 'who,' 'where,' 'how,' 'what,' and 'when' of the research, so that the reader can understand the research and how it relates to their own situation.

It will take some time to establish a patient research voice in academic publications, so it is important to foster other ways to write and speak about peer researchers in other venues that patients read. This initially might include

health associations related to the research, seniors magazines such as *Zoomer*, or publication hubs for peer research like the PRISM/PaCER hub.

Dependability

This is a confirmation of how carefully the research was done, what problems arose, and how the changes made affected the study and the results. Dependable research is transparent, meaning that nothing is hidden. Sometimes, standardizing the process increases dependability but can decrease credibility. As JW, one of our researchers, commented when administering their standardized questions: "We felt good that we had a standardized questionnaire and that we were doing the questionnaire the right way, but the answers were boring and left a lot of questions unanswered" (Marlett & Emes, 2010, p. 86).

Objectivity

Academics are most likely to use this objectivity standard against research done by patients and communities. They may feel that peer researchers are biased and tempted to distort the information to reflect what they want to find. Research is not about proving the researchers' thoughts and knowledge but about looking at every event or piece of information as if it were happening for the first time. Objectivity means that every observation is open to question. Every researcher, regardless of age, must struggle to avoid having their biases affect their observations. Research can range from a very simple observation to a very complex investigation, but regardless of the size or complexity, all research is a process of discovery.

In this chapter, we have attempted to provide a broad overview of how health researchers and healthcare providers can understand and support peer research. The following quote is from two of the authors of *Grey Matters* in their field notes:

"It would have been so easy to take the data and to write it up as an academic, the data spoke to the theories that I was interested in. It was a hard decision. In the end, perhaps there is a place for both, research that speaks to theory and research that speaks to everyday life. The ideal would be to have both goals possible in the same method; at least it's something to work toward."

Summary

This chapter explored the basics of peer research methods in a variety of health-related research options to extend patient engagement. Those wishing to become peer researchers may also understand why peer research is different from other forms of qualitative research.

This chapter completes the second section, combining the findings of a number of research projects. As such, it provides the background for PaCER training for those health researchers wanting to include patients in their research plans and research teams and thinking about hiring trained patients to augment existing or proposed grants. It is also provided for researchers who have either taken PaCER training or worked through the companion *Grey Matters* and this manuscript, and who are willing to experiment with training the patients and communities they work with to develop their own version of peer research.

Research students and researchers who identify with a patient or community population might use this chapter to hone their personal research skills. It is hoped that teams who are working with peer researchers may consider new ventures to create new models of peer research. This chapter is, above all, intended to incite experimentation and sharing of engagement methods. It is not a manual but a set of ideas from 30 years of experimenting with engagement methods.

The next section uses the methods and theories of Section 2 to extend peer research to support social innovation and social enterprise to bring patients and communities into the transformation in health that is 'just over the hill.'

Questions for Discussion

1. Have you used methods similar to these as part of your research? If so, how have peer research methods differed, if at all?
2. What methods seem to capture your ideas about peer and community research?
3. What obstacles do you see in adapting these peer methods to your patient engagement practice?
4. How might you incorporate peer research into your future plans?

Resources

The following process is one summary of a research method using the stages presented throughout this chapter. It captures a single iterative cycle of data collection, analysis, interpretation, and planning the next cycle.

Table 8.5 *Iterative Cycle of Data Collection, Analysis, Interpretation, and Planning*

Collect your data	Prepare to listen and look for incidents in the data you are about to collect. Incidents are actions (stories), and elements of stories and indicators of actions (metaphors, strategies). Coding occurs at the category level as incidents refine, challenge, or support the category code. As new data is captured as incidents (using cards or computer programs), question the incident using the standard questions and make notes on how the answers deepen your understanding of the incident and be prepared to compare with other incidents or categories.
Question, code, and constantly compare incidents	**Question** each incident, in turn, to learn how it relates to your main concerns and what ideas it brings to your analysis. Based on your questioning, refine each incident to reflect the answers to your questions. 'Rehearsing children' might change to incident codes 'rehearsing children for the social worker visit,' 'rehearsing children-vulnerability,' or 'rehearsing children to be allies.' **Constantly compare** each incident to the incidents within categories of other incident codes, and from this sorting process, you form categories that share the same meanings and/or properties. As categories form, you compare new incidents to the emerging categories. You continue to ask questions of the contents of each category to test its strength in making sense of the main concern and how the category could be used to resolve or find solutions to the main concern. Categories are flexible and combine and divide as new incident codes are added. When the **core category,** that best category that you have identified, you compare each remaining category to the core category and to each other to find the pattern of categories that make up your working theory.

Table 8.5 (*continued*)

Memo about emerging categories	Write field notes about the methods and findings each time you collect data. Memo as questions arise about connections and ideas about emerging theory. If you are sharing analysis with your teammates, you might follow one category throughout the analysis to learn about how categories evolve or dissolve. As you come close to the core category, focus on which category seems to stand out and how your category might relate to or challenge that emerging category as theory. Continue to memo selectively about which category best seems to explain the main concern and is the foundation of your theory.
Shared analysis, with the researcher team and the principal investigator	This is an opportunity for each team member to present and be questioned about one of their categories. Initially, each person presents and works with the team to collect and consolidate any incidents or concepts that fit with their category. Each person has at least one category to work with. When you are selecting the core category, each person presents what they consider to be the best category until consensus is reached. Each person then presents how their personal category relates to the core category. During this shared analysis, the team also divides up the remaining categories and each team member works with that category to prepare a poster for REFLECT.
Disseminating research findings	Next steps allow the team and the principal investigator to decide how to disseminate the results from the Reflect focus group paying attention to the consumer targets, academic teams, publication.

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