

# Patient-Guided Tours: A Patient-Centered Methodology to Understand Patient Experiences of Health Care

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## ABSTRACT

**PURPOSE** The experience-based design approach using patient-guided tours (PGT) has been suggested as an effective way to understand the patient experience and may better allow the patient to recall thoughts and feelings. The objective of this study was to assess how patients with a disability perceive the effectiveness of PGTs for understanding their experiences of receiving primary health care.

**METHODS** A qualitative study design was used. Participants were chosen by convenience sampling. The patient was asked to walk through the clinic as they would on a “typical visit” while describing their experiences. They were questioned about their experience and perception of PGTs. The tour was audiotaped and transcribed. The investigators took field notes and completed thematic content analysis.

**RESULTS** Eighteen patients participated. The main findings were: (1) Touchpoints and physical cues were effective in eliciting experiences that participants stated they would not have recalled using other research methods, (2) The ability for participants to show the investigator aspects of the space that impacted their experience enabled the investigator to “see through their eyes” resulting in ease of communication and a sense of empowerment, (3) PGTs encouraged individuals to be active participants which fostered comfort and collaboration, and (4) PGTs may exclude those that are severely disabled.

**CONCLUSION** This method was perceived as effective at eliciting experiences of patients with a disability. It has benefits over more traditional research methods by allowing the participant to refresh their memory at “touchpoints” and enabling them to be active participants.

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## INTRODUCTION

As we move to a patient-centered model of care, we emphasize patient needs and preferences within their own social context.<sup>1</sup> Literature suggests that this model of care enhances patient-physician communication<sup>2</sup> and therefore encourages a collaborative approach to health care.<sup>3</sup> Implementing this type of care model requires various changes including system-level changes and shared decision making.<sup>4,5</sup> Traditionally, efforts have been focused on measuring patients' attitudes rather than experiences. The United Kingdom's National Health Service (NHS) experience-based design (EBD) approach has shown patient-guided tours to be an effective way of understanding the experience through the patient perspective.<sup>6</sup> Patient-guided tours (PGT) have allowed patients to identify areas of the clinic that appear in alliance with patient-centered care, and those areas that do not. Walking through the environment with the investigator allows the patients to refresh their memory at various “touchpoints,” helping them to recall thoughts and feelings they experience during a typical visit which may not have been identified using other modalities of assessing patient perception of care such as questionnaires.<sup>7</sup> A “touchpoint” is defined as a time of interaction between the patient and health care team/facility within the patient's health care journey. Psychological research on personal narratives supports this type of approach in examining patient experiences as they occur within a specified environment.<sup>8</sup> As the patient is familiar within the environment where the study is conducted, it may reduce the power differential of the researcher in a positive way so that patients are more likely to share their narrative.<sup>7</sup>

Some researchers have used this method to effectively understand participant experiences, including our study to better understand experiences of patients with

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disabilities in receiving primary health care, but to our knowledge there are no studies to assess the effectiveness of this methodology.<sup>9,10</sup> Given the perceived benefits of this method and potential superiority over more traditional methods such as questionnaires, interviews, and focus groups in answering certain research questions, we wanted to understand how well patients felt this method captured their experiences in addition to any potential benefits and challenges of using this methodology.

## METHODS

This study was conducted at the Mount Sinai Academic Family Health Team, a primary care clinic in Toronto, Canada. Convenience sampling was chosen for feasibility; the study team comprised of 2 physicians (S.W., J.C.), a social worker (C.H.) and the quality lead and administrator at the time (D.A.). The principal investigator (PI) (S.W.) asked clinic physicians to identify patients with a disability that might be able to participate in the study. A study team member (D.A.) then called these patients to assess eligibility and obtain consent.

The inclusion criteria were: (1) patients of the clinic, (2) age 18 years or older, (3) individuals identified as having any disability, (4) English speaking, (5) cognitively intact/power of attorney who was cognitively intact and provided consent on their behalf, (6) consent to participate and be audio recorded. The exclusion criteria were participants who did not consent to participate, patients known to the investigators before the study, and those who would be unable to complete the patient-guided tour such as those with severe physical limitations, language barriers, learning disabilities, or cognitive impairments even with the use of aids and/or support people. The time frame for sampling and data collection was from February 2016 to December 2016.

Approval from the Research Ethics Board of the University of Toronto was obtained.

### Sample Size

Sample size was not set from the onset but instead determined by level of saturation of findings in that no new themes emerged, and existing themes continued to appear.<sup>11</sup> Investigators aimed to recruit a minimum of 10 participants.

### Patient-Guided Tour

Two investigators (S.W., D.A.) completed the tours (1 investigator per tour). Participants led the investigator through the building and clinic as they would on a typical visit. They started at the entrance and led the investigator through the various areas of the building and clinic, including the check-in and triage process, with the clinic room as the destination. They were advised to comment on their feelings, thoughts, and experiences throughout the process. They were also asked to reflect and comment on their experience and perception of PGTs. Investigators completed field notes during the

tour and used prompts as needed. Tours lasted 30 to 45 minutes. Patient demographic characteristics were collected via a survey at the end of the tour.

### Data Collection

Patients were recorded during the tour and then audio recordings were transcribed verbatim. A process map describing the typical office visit was used as an aid. Investigators paid particular attention to the physical space, activity, actors, acts, sequencing of events, and feelings.

### Data Analysis

A thematic content analysis was used to identify, analyze, and report patterns within the data.<sup>12,13</sup> It was used during the data collection period as an iterative process that allowed the results of the analysis to inform future interviews. This method commenced with all investigators (S.W., J.C., C.H., D.A.) reading over the PGT transcripts and field notes to become immersed in the data. Subsequently, open coding line by line of each transcript was conducted independently by S.W., J.C., and C.H. The group then met to compare findings before grouping themes into broader categories. Any disagreements were resolved by discussion. Throughout the process, the findings were constantly compared with previous findings, which allowed the investigators to identify common patterns or differences. The transcripts were reviewed again as a group with the identified themes in mind and this process was repeated until no new themes were found. Investigators (S.W., J.C., C.H.) reviewed field notes and transcripts after every 2 to 4 patient-guided tours to identify any major themes/issues with prompts.

The field notes contained the observations made by the investigators during the tours and were reviewed to assess if they supported the emerging themes as well as to identify any repeating observations that were not included in the transcripts. Please see Walji et al for more details on the method.<sup>10</sup>

## RESULTS

Eighteen participants with various disabilities were included in this study and saturation was achieved. Seventeen of the participants completed the demographic survey (Table 1).

Four major themes regarding the methodology of PGTs emerged: (1) touchpoints and physical cues were effective in eliciting experiences that participants stated they would not have recalled using other research methods; (2) the ability for participants to show the investigator aspects of the space that impacted their experience enabled the investigator to “see through their eyes” resulting in ease of communication and a sense of empowerment; (3) PGTs encouraged individuals to be active participants which fostered comfort and collaboration; (4) PGTs may exclude those that are severely disabled or those with some medical conditions.

### Touchpoints and Physical Cues

Participants reported that this method of feedback was particularly effective in conveying in-depth information. Being in the actual physical space and enacting the experience helped participants accurately assess the space by eliminating room for error relating to poor recall. It also triggered memories and emotions which enabled in-depth communication of their experiences. Participants described the process as “being alive” and reported that the memories and emotions that were triggered by visual cues would have otherwise been forgotten using traditional research methods such as a survey or an interview.

“I could fill out a survey about this place but to actually come and see, and the view, it’s totally different” [P1]

“I don’t think I would have volunteered it or even...in an interview, I don’t think I would have identified it” [P2]

“I’d never think of writing it...you don’t think of that when you’re just writing down words.” [P3]

“You could just ask me some questions over the phone, or in person, but to actually walk me through and see the process happen itself is...it’s different. It’s got more verve. Like, it’s more alive.” [P6],

The act of booking and visiting their primary care physician was described as a process that was second nature to the participants, but being in the physical space and acting out the motions allowed participants to stop and reflect on their experiences in a more detailed fashion.

“On some level, I was aware of it, but it’s like a lot of you know, like, when you’re driving, you don’t pay attention to every bump on the road...so I wouldn’t have thought of that, and this process surfaced for me things that...I never consciously thought about it. Yeah, so, it’s a good technique.” [P2]

### “See Through Their Eyes”

Performing the tour allowed the participants to point out things or demonstrate difficulties that would have been harder to convey verbally or by written communication.

“Because I can tell you exactly what I’m feeling coming here, versus having to put it in a sheet. I can’t be bothered” [P5]

“For me, it’s easier when I’m there to show you” [P1]

Though the experiences sought were those that went beyond just the experiences of the physical space, participants found it particularly helpful to show the investigator various aspects of the building and clinic that affected their experience. They were able to use gestures and body language to point at things and could describe their experiences without the need to describe aspects of the building they are referring to as the investigator is witnessing and viewing the space at the same time as the participant. Participants expressed that this methodology may make it easier for some

patients to communicate their thoughts and feelings, for example those experiencing intellectual or communicational disabilities or those with language barriers.

“Well with the learning disabilities, it’s easier for me to speak than read and write” [P1]

Many participants described this particular methodology as helping them convey their true experiences by allowing the investigator “to see through their eyes” or “step into their shoes.” The process involved felt like a reenactment of a typical clinical visit and so participants described the process as a “lived experience” that the investigator was going through with the participant.

“I believe in the whole experience. Just saying something is only part of the experience. But physically experiencing something together with the verbal feels a little more, like, ‘Aah, so that makes sense.’ It’s more lived.” [P6]

“When you come on a tour with me, you see through my eyes” [P1]

**Table 1. Participant Characteristics (n = 17)**

Characteristic	No. (%)
Sex <sup>a</sup>	
Female	11 (69)
Male	5 (31)
Born in Canada	
Yes	9 (53)
No	8 (47)
Ethnic background	
White, North American	7 (41)
White, European	4 (24)
South Asian	2 (12)
Southeast Asian	1 (6.)
First Nations	1 (6)
Middle Eastern	1 (6)
Other	1 (6)
Disability <sup>b</sup>	
Physical disability	13 (76)
Sensory disability (impaired vision/hearing)	9 (53)
Mental illness	2 (12)
Learning disability	1 (6)
Developmental disability	1 (6)
Other (not specified)	3 (18)
Annual income <sup>a</sup>	
<\$30,000	10 (63)
≥\$30,000	6 (37)
Participation	
On behalf of themselves	16 (94)
On behalf of a family member	1 (6)

Note: All participants aged 18 years or older.

<sup>a</sup> One participant chose not to answer.

<sup>b</sup> Multiple responses were possible.

"I'm glad you're doing this...because so many things get overlooked, unless you are disabled yourself or you are close to someone in your family or a close friend and you see...the things we go through." [P7]

### Active Participants

The act of leading the investigator through the clinic in PGTs was described by participants as putting the participant in the driver's seat and allowing them to feel like active participants in the process. This resulted in them feeling more comfortable and empowered and encouraged them to share.

"The more comfortable you make the patient, the more they're actually able to collaborate and cooperate...It frees a person to be an active participant and really work, uh, with their care." [P2]

This shift in power differential compared with traditional methods allowed participants to feel valued and seen as a whole person. It also encouraged the development of a relationship with the participant and investigator.

"I think this procedure that you've developed is better than a written survey because it takes in the person...I mean, there's a relationship involved, a personal relationship involved in this...somebody would be hearing that." [P4],

Participating in the PGT was described as valuable by these participants; they described relief in being able to truly convey their experiences and that the PGT allowed them to do this in a more objective fashion.

"I think the personal contact and the listening that you do, people do like to be listened to, you know? So that to me, enhances the experience." [P4]

### PGTs May Exclude

Participants described that despite the benefits of this methodology, there may be some groups of individuals that would not be able to participate such as those markedly restricted in mobility, those with severe mental health conditions or those who are not able to endure a 30- to 45-minute period with significant moving around.

"Maybe if I was on crutches or, you know, had a more...[was] more disabled than I am, uh, maybe I would have concerns coming along." [P4]

"I don't know if you want to try to limit it to certain amounts of time." [P3]

Despite the investigators being cognizant of privacy concerns, some participants, particularly those who reported having mental health disabilities, described feeling uncomfortable speaking of their experiences during a routine clinic day with the usual patient and staff traffic throughout the building. This was also recorded by investigators in their field-noted observations of some participants using more hushed tones in the presence of nearby patients and staff.

"I felt good about speaking about all my confidential things in this examining room. Because I would have not done it in the reception area" [P1]

"I didn't want to know their...my business. I didn't want to tell them what's wrong with me" [P8]

## DISCUSSION

Our findings support the value of PGT methodology in understanding patient experiences. Physical cues and touchpoints enabled participants to recall experiences, thoughts, and feelings they would not have recalled otherwise. It was perceived as an effective method and perhaps superior to other research methods such as interviews or focus groups in answering certain research questions. There has been growing interest in exploring more novel methods of qualitative research that connect the environment to the patient's thoughts, feelings, and experiences.<sup>7</sup>

Literature suggests that a more active role of the patient in clinical care and improvement initiatives results in enhanced collaboration and communication.<sup>2,3</sup> The adoption of participatory research methods, where the line between participant and researcher is less distinct, has occurred as a result.<sup>14</sup> The PGT design involves the patient leading the investigator which may shift the power differential that can exist in a more traditional interview format.<sup>15</sup> Our participants commented on the feeling of empowerment related to their role as active participants within this process which enhanced comfort and collaboration. They described a connection between the investigator and themselves which allowed them to feel more involved in the process.

Many participants commented how the PGT method allowed them to convey their story more easily; the physical cues and touchpoints as reminders, as well as the ability to show the investigator an area of interest rather than describe it, contributed to this finding.

The importance of conveying the "lived experience" to the investigator was seen as a particular advantage of this method. Participants voiced feeling "seen" or "heard" by physically displaying to the investigator what their journey in the health care setting entails. Aside from the ability to convey more in-depth information of their experiences, participants described a sense of relief and commented on the value of being able to share their experiences in a way they felt captured their story.

Patient-guided tours may be well suited for research studies where the physical space directly and indirectly impacts patient experience. For example, in this study, leading the investigator allowed the participants to describe how the physical space affected their experiences and subsequently their interactions with the health care team. Studies utilizing the PGT method have demonstrated similar findings with participants effectively highlighting areas of the physical environment that may benefit from improvement.<sup>10,16</sup>

Our study assessing experiences of patients with disabilities with primary care, as well as others, demonstrates the impact of the physical space on the patient perception regarding the quality of care and value of the department as well as the quality of the interaction of the subsequent clinical encounter.<sup>10,16,17</sup> Furthermore, those who have utilized this method have noted how participants are effectively able to highlight areas for improvement.<sup>9,10</sup> Therefore, PGTs may be particularly useful in assessing how the physical space affects patient experience and in gaining deeper insights into improvement opportunities. Alternatively, independent of seeking direct feedback about the physical space, PGTs can be used to assess any experiences where the physical space is likely to provoke resurgence of memories, feelings, and emotions such as a labor and delivery floor/room. It may be particularly useful to assess experiences of vulnerable populations by allowing the participant to lead the tour and take on the role of active participant.

### Limitations

Drawbacks of this method include that it is time consuming. Additionally, it was noted both by participants and investigators that there were various times participants were hesitant to share their experiences due to a lack of privacy during the tour and that participants were able to disclose more personal experiences alone in the clinic room with the investigator. It is also limited to those who are physically capable of participating; those who have severe mobility issues or disabilities and most likely in greater need of care were unlikely to participate. Although our data captures the perceived effectiveness of this method, we did not have data to complete objective comparisons between different research methods; this may be an area for future research. As our study did not focus on a group of patients with one specific disability, we were not able to assess how a specific disability impacted PGTs which may be of relevance to some health care settings. We also acknowledge that limiting the study to participants that only speak English omits a group of individuals who may encounter additional barriers in accessing health care. Finally, lack of triangulation of findings is a limitation of our study. Future studies feeding our findings back to participants and clinic staff would be of value.

### CONCLUSION

Patient-guided tour is a novel and patient-centered method that is effective for understanding the experiences of patients receiving primary health care. It may be superior to other research methods in allowing patients to fully share their experience; allowing them to remember experiences they wouldn't have otherwise remembered and triggering feelings and emotions to enable more in-depth feedback in a way that is easier to describe. Having the patient lead the tour as an active participant was beneficial in fostering comfort, trust, and collaboration. Given these benefits, this method should

be considered by researchers when seeking out patient experiences of health care settings.



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**Key words:** patient-guided tour; experience-based design; touchpoints; patients with disabilities; qualitative research methodology

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### REFERENCES

- Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care*. 2011;23(5):510-515. [10.1093/intqhc/mzr024](https://doi.org/10.1093/intqhc/mzr024)
- McCormack LA, Treiman K, Rupert D, et al. Measuring patient-centered communication in cancer care: a literature review and the development of a systematic approach. *Soc Sci Med*. 2011;72(7):1085-1095. [10.1016/j.socsci.med.2011.01.020](https://doi.org/10.1016/j.socsci.med.2011.01.020)
- Britten N. Commentary on series: The research agenda for family practice/family medicine and primary care in Europe. Part 3. Results: person-centred care, comprehensive and holistic approach. *Eur J Gen Med*. 2010;16(2):67-79. [10.3109/13814788.2010.481710](https://doi.org/10.3109/13814788.2010.481710)
- Epstein RM, Street RL Jr. The values and value of patient-centered care. *Ann Fam Med*. 2011;9(2):100-103. [10.1370/afm.1239](https://doi.org/10.1370/afm.1239)
- Reed P, Conrad DA, Hernandez SE, Watts C, Marcus-Smith M. Innovation in patient-centered care: lessons from a qualitative study of innovative health care organizations in Washington State. *BMC Fam Pract*. 2012;13:120. [10.1186/1471-2296-13-120](https://doi.org/10.1186/1471-2296-13-120)
- NHS Institute for Innovation and Improvement. The ebd approach - experience based design. Published 2009. Accessed Nov 2015. [https://nhselect.nhs.uk/uploads/files/1/EBD%20Guide\\_single.pdf](https://nhselect.nhs.uk/uploads/files/1/EBD%20Guide_single.pdf)
- Miaux S, Drouin L, Morency P, Paquin S, Gauvin L, Jacquemin C. Making the narrative walk-in-real-time methodology relevant for public health intervention: towards an integrative approach. *Health Place*. 2010;16(6):1166-1173. [10.1016/j.healthplace.2010.08.002](https://doi.org/10.1016/j.healthplace.2010.08.002)
- McAdams DP. Personal narratives and the life story. In: John OP, Robins W, Pervin LA, eds. *Handbook of Personality: Theory and Research 3rd Ed*. The Guilford Press; 2008:242-262.
- Locatelli SM, Turcios S, LaVela SL. Veterans' experiences of patient-centered care: learning from guided tours. *Patient Exp J*. 2014;1(1):88-94. <https://pxjournal.org/journal/vol1/iss1/14/>
- Walji S, Carroll JC, Haber C. Experiences of patients with a disability in receiving primary health care: using experience-based design for quality improvement. *Can Fam Physician*. 2021;67(7):517-524. [10.46747/cfp.6707517](https://doi.org/10.46747/cfp.6707517)
- Urquhart C. *Grounded Theory for Qualitative Research: A Practical Guide*. Sage Publications; 2013.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2008;3(2):77-101. [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)
- Vaismoradi M, Jone J, Turunen H, Snelgrove S. Theme development in qualitative content analysis and thematic analysis. *J Nurs Educ Pract*. 2016;6(5):100-110. [10.5430/jnep.v6n5p100](https://doi.org/10.5430/jnep.v6n5p100)
- Baum F, MacDougall C, Smith D. Participatory action research. *J Epidemiol Community Health*. 2006;60(10):854-857. [10.1136/jech.2004.028662](https://doi.org/10.1136/jech.2004.028662)
- Rubin AT. *Rocking Qualitative Social Science: An Irreverent Guide to Rigorous Research*. Stanford University Press; 2021.
- Locatelli SM, Turcios S, LaVela SL. Optimizing the patient-centered environment: results of guided tours with health care providers and employees. *HERD*. 2015;8(2):18-30. <https://pxjournal.org/journal/vol1/iss1/14/>
- Becker F, Douglass S. The ecology of the patient visit: physical attractiveness, waiting times, and perceived quality of care. *J Ambul Care Manage*. 2008;31(2):128-141. [10.1097/O1.JAC.0000314703.34795.44](https://doi.org/10.1097/O1.JAC.0000314703.34795.44)