



# The Renal Community Photo Initiative: A Program Report in Ontario, Canada

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## Abstract

**Purpose of Program:** We initiated the Renal Community Photo Initiative to better understand why some hemodialysis users express significant capacities for resilience and hope, demonstrating outward-looking perspectives and enjoying a rich quality of life.

**Sources of Information:** “Photovoice” is a participatory research methodology that encourages individuals to develop positive self-perceptions with photography. Photovoice empowers participants as informants within their communities. Visual arts researchers surveyed existing Photovoice studies to identify gaps in knowledge to be addressed in this study, including challenges related to fostering participant agency and social action. Images and logs were collected and reviewed during organized, participant-led substudy groups. These meetings provided researchers with core study values and direction as to how the images and additional information should be used to raise awareness about living with chronic kidney disease.

**Methods:** To address the complexity of the human condition, the Renal Community Photo Initiative offered participants an array of diverse and accessible image-making techniques. No narrative directives for image-making were provided. This qualitative, interdisciplinary, participant-centric study invited adult chronic hemodialysis patients in 4 dialysis units in London and Stratford, Ontario, to participate. The research team designed a selection of different, accessible photo technologies for participant use. Eligible participants were invited to select photographic technologies and given the additional option to write accompanying logs. Researchers organized substudy meetings for participant-led focus groups to discuss core study values and personal encounters with images and image-making. Participants directed how their generated images should be shared with the public and researchers.

**Key Findings:** A total of 40 participants have been recruited to date, producing more than 1600 images and an archive of handwritten logs. Three participant-led focus groups have established priorities for image sharing and a core set of values for subsequent study phases. A series of public presentations of participant images took place. The research team will pursue further public presentation opportunities and the development of a suitable research database.

**Limitations:** Organizing and categorizing images for access in an interdisciplinary research database remains a challenge. Current health and safety protocols related to COVID-19 require the study to pause recruitment and substudy meetings and reassess immediate outputs for visuals.

**Implications:** A qualitative study of this scope offers a new model for participant agency and collaboration. It requires the onboarding of interdisciplinary researchers to effectively engage with its significant image and log archive. Participants should remain involved in directing future steps for disseminating their images. Following substudy directives, researchers are developing visuals for health care and public settings, and determining opportunities for participants to share their experience in both clinic- and public-based settings.

## Abrégé

**Objectif du programme:** Nous avons lancé la Renal Community Photo Initiative afin de mieux comprendre pourquoi certains utilisateurs de l'hémodialyse font preuve d'importantes capacités de résilience et d'espoir, sont tournés vers le monde extérieur et jouissent d'une riche qualité de vie.

**Sources:** «Photovoice» est une méthodologie de recherche participative qui encourage les individus à développer une perception de soi positive grâce à la photographie. Photovoice permet aux participants de devenir des informateurs au sein de leurs communautés. Les chercheurs en arts visuels ont mené une enquête sur les études existantes de Photovoice afin de révéler les lacunes dans les connaissances qui pourraient être comblées par la présente étude, notamment les défis liés à la promotion de la participation et de l'action sociale des participants. Des images et des registres ont été recueillis



et examinés lors de sous-groupes d'étude organisés et dirigés par les participants par les participants. Ces réunions ont permis aux chercheurs de définir les valeurs fondamentales de l'étude et d'indiquer comment utiliser les images et les autres informations pour sensibiliser les gens à la vie avec maladie rénale chronique.

**Méthodologie:** Afin d'aborder la complexité de la condition humaine, la Renal Community Photo Initiative a offert aux participants une gamme diverse et accessible de techniques de création d'images. Aucune directive narrative n'a été fournie pour la création des images. Cette étude qualitative, interdisciplinaire et axée sur les participants a invité des adultes suivant des traitements d'hémodialyse chronique dans quatre unités de dialyse de London et Stratford (Ontario) à participer. L'équipe de recherche a conçu une sélection de technologies photographiques diverses et accessibles à l'usage des participants. Les participants admissibles ont été invités à choisir des technologies photographiques et à tenir un journal s'ils le souhaitaient. Les chercheurs ont organisé des réunions de sous-étude pour des groupes de discussion dirigés par les participants afin de discuter des valeurs fondamentales de l'étude et des expériences personnelles avec les images et la création d'images. Les participants ont établi la façon dont leurs images devraient être partagées avec le public et les chercheurs.

**Principaux résultats:** À ce jour, 40 participants ont été recrutés et plus de 1 600 images ont été produites, de même qu'une archive de journaux manuscrits. Trois groupes de discussion dirigés par les participants ont établi les priorités pour le partage des images ainsi qu'un ensemble de valeurs fondamentales en vue des phases ultérieures de l'étude. Plusieurs présentations publiques des images des participants ont eu lieu. L'équipe de recherche poursuivra les présentations publiques et l'élaboration d'une base de données de recherche.

**Limites:** L'organisation et la catégorisation des images pour y accéder dans une base de données de recherche interdisciplinaire demeurent un défi. Les protocoles actuels de santé et de sécurité liés à la COVID-19 empêchent le recrutement et les réunions de sous-étude pour le moment et imposent de réévaluer les résultats immédiats pour les visuels.

**Conclusion:** Une étude qualitative de cette envergure offre un nouveau modèle pour la participation et collaboration des patients. Elle exige l'intégration de chercheurs interdisciplinaires afin d'exploiter efficacement ses importantes archives d'images et de journaux. Il importe que les participants demeurent impliqués dans la direction des prochaines étapes de diffusion de leurs images. Suivant les directives de la sous-étude, les chercheurs développent des visuels pour les soins de santé et les milieux publics, et recensent les occasions pour les participants de partager leur expérience tant dans les milieux cliniques que publics.

## Keywords

photography, chronic hemodialysis, patient-oriented research, public display, knowledge translation

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## Introduction

We began the Renal Community Photo Initiative to better understand why some hemodialysis users express significant capacities for resilience and hope, demonstrating outward-looking perspectives and enjoying a rich quality of life. We established an interdisciplinary study that would expand on gaps in Photovoice methodology by inviting patients receiving chronic dialysis treatment to provide their unique first-person perspectives through uninhibited image-making and writing.

The objectives of this project were (1) to provide participants with numerous photo-based opportunities for engaging

in, and responding to, their lived experiences on dialysis; (2) to encourage participants to reflect on and record their individual and their community's (dialysis community) strengths, challenges, and concerns in languages that embrace open-endedness and ambiguity; (3) to promote dialogue about individual and collective issues (practical, emotional, psychological) through individual and group discussions of participant images; (4) to reach and inform health care providers, interdisciplinary researchers, policymakers, funding bodies, and the community at large with affective images that uniquely express participants' lived experiences; (5) to offer new strategies for fostering participant collaboration and agency toward meaningful change.

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## Photovoice

“Photovoice” methodology is used to invoke personal and community-based change. Initially established as Photo Novella by Wang and Burris<sup>1</sup> and Wang et al,<sup>2</sup> this empowering research approach invites individuals to reflect upon their individual concerns—and subsequently the strengths and concerns of their communities—by producing photographs. Photovoice fosters agency at both individual and collective levels.<sup>3</sup> For example, participants in health care-centric Photovoice studies are encouraged to share subjective insights that are often overlooked while treatment outcomes are decided and dictated by those in the power of their care.

The Photovoice process facilitates partnerships, via discussion, between participants, researchers, and stakeholders and emphasizes equitable participation. This equity emphasis makes Photovoice an attractive research method for addressing marginalized communities.<sup>4</sup> However, and as Kuratani and Lai<sup>5</sup> have noted, numerous Photovoice studies exhibit a “lack of social action plan.” Researchers benefit from participants’ evocative data (shared in publications or exhibitions), yet if no social action plan is implemented that fosters significant shifts in participant communities, participants may feel abandoned and even “objectified” by these studies.<sup>5</sup>

Our study’s design promotes agency and accessibility for all potential participants, including those with lower levels of energy and/or reduced mobility due to treatment. The project was conceived in London, Ontario by interdisciplinary researchers in clinical research (Lawson Health Research Institute) and the Department of Visual Arts (Western University). The Renal Community Photo Initiative surveyed previous Participatory Action Research (PAR) studies that incorporate Photovoice and discerned conceptual and social gaps in existing methodologies. We also examined collaborative studies in Canada between clinical researchers, patients, and visual artists.<sup>6</sup> Following initial recruitment of participants, the research team developed substudy groups in which participants acted as advisors to direct subsequent stages of knowledge sharing. A number of these substudy participants acted as on-site ambassadors for public image-sharing opportunities. Project participants serve as co-authors/editors of this Program Report and an accompanying creative component.

## Methods

This study offered participants varied modes of personal expression by embracing both representational and abstract photo modalities. As research on Photovoice identifies risks of inadequately attending to social action, this underscored participants’ agency.

## Settings

This study involved participants from hemodialysis units in Southwestern Ontario, Canada: London Health Sciences

Centre (LHSC) dialysis units at University Hospital, Victoria Hospital and satellite units of LHSC at the Kidney Care Centre (KCC), Westmount Shopping Centre and The Huron Perth Healthcare Alliance’s (HPHA) Dialysis Unit in Stratford. These different locations provided a variety of insights reflecting urban and rural settings.

Participant photography took place in their health care environments, homes, and throughout their day-to-day lives. Film images were processed in a Toronto photo lab. High-resolution scans of film-based and paper-based images were made in the Department of Visual Arts at Western University. All images (digital photos, film-based and paper-based images, and high-resolution digital scans) are stored on secure hard drives and housed in the Lawson Health Research Institute. Our study protocol states that analog and digital files will be stored at LHSC and Lawson for 15 years.

## Design

This was a qualitative, participant-focused, and image-centric survey exploring understudied and/or underrecognized aspects of patient quality of life. Participants were invited to engage with and respond to their personal experiences of life on dialysis, both within and beyond their treatment environments. An initial goal of our approach was to catch the attention of participants through the production of images that register familiar environments in unfamiliar ways. Diverting from Photovoice approaches, this study provided participants with high levels of flexibility and experimentation. Photovoice strategies invite participants to produce photographs with a camera and usually administer predetermined directives or expectations: participants are instructed to take a set number of photographs addressing challenges of renal illness, or photograph solutions to challenges faced as a result of renal illness. We avoided leading participants with prompts, statements, or themes. These directives delimit the range of individuals’ engagements with their surroundings, as well as the range of potential image outcomes, before the act of photography has even begun.

Participants were given instruction for using their chosen camera systems (see below) and were given a set amount of time in which to produce images (3 weeks). Participants were also instructed in best practices when photographing other individuals in public and private settings and were instructed in gaining written consent when photographing family members, friends, health care providers, and so on in private spaces. Any images of individuals for which reasonable consent was not attained were not eligible for inclusion in the Photo Initiative archive.

Participants chose from 5 user-friendly, accessible camera technologies: digital cameras, point-and-shoot film cameras, pinhole cameras, instant film cameras, and cyanotype paper. These camera systems also accounted for participants experiencing limited energy levels or mobility. Most participants were able to comfortably use their

chosen technology after a brief, in-person demonstration. If a participant felt overwhelmed or uninspired by a camera technology, they could request a different camera system and begin their period anew. Participants could determine the number of images created, though certain camera technologies determined the number of images available: for example, a film camera provided 36 exposures, whereas a digital camera offered hundreds of photo opportunities. In addition, participants were given the option to contribute corresponding written logs of their image-making, with the parameters of what they share in these logs left open to them.

We aimed to promote the production of images that both quantify and respond, directly and indirectly, to the participant's affective experiences. Multiple possibilities for visual engagement encouraged participants to think about—and experiment with—the ways they image their lives. Different camera technologies have the capacity to put specific faces on experience. While introducing an important element of play into the picturing of experience, we also took advantage of an underexplored terrain within qualitative health care research: photography's affective potential. Some of our cameras facilitated the production of what is historically called “straight photography”—representational images that depict a scene as the subject frames it in their camera's viewfinder. Interpretation of these images tends to be narratively driven, but cameras remain open to visual experimentation through photographing in nontraditional ways, such as experimenting with multiple or long exposure. Other photo technologies did not allow the participant to use a viewfinder in composing (pinhole camera) or relied entirely on abstracted, tactile techniques (cyanotype paper).

Study participants were invited into one of three interactive substudy groups with other participants, researchers, and invited stakeholders. Participants determined core values for the study and how best to share this study experience within their immediate communities and with the broader public. Each group met twice. In the first meeting, participants discussed images and personal experiences, articulated core values, and workshopped exhibition and information-sharing opportunities. In the second meeting, researchers proposed displays devised from the first meetings and received feedback and further direction from participants.

Film negatives, instant film images, and cyanotype images were scanned on Western Campus at the John Labatt Visual Arts Centre. Scanning film negatives, instant film, and cyanotypes is an archival necessity, as some of these materials change over time. Scanning also enables images to be enlarged for presentation either in print form or as digital projections. In cases where participants overexpose or underexpose their film, the researchers could often salvage image information with digital postprocessing.

## Recruitment

Participants were recruited, informed, and consented during dialysis treatments. A number of nursing staff supported this study and played instrumental roles in introducing the research team to potential participants. Visits to the dialysis units offered researchers opportunities to discuss the Initiative one-on-one and demonstrate the use of different camera systems.

## Study Process and Procedures

This research study received approval by the Office of Human Research Ethics, Western University, Project ID: 108649. Once consented, participants were given time to decide which camera technology they wanted to use and were trained in camera use as needed. If they had chosen an analog, 35-mm pinhole camera, participants had the additional option of choosing between color or black and white film. Participants received their chosen technology for 3 weeks with support from researchers as needed.

At the end of 3 weeks, participants returned their camera systems; some requested additional time. Participants with digital or instant film cameras were asked to not share images on public forums (social media). We processed all film negatives and archived digital photographs to secure external hard drives. All analog technologies (film, cyanotype prints) were scanned in high resolution and these files were archived on secure external hard drives. After processing films, researchers met with individual participants to review their images for the first time and gather valuable information.

## Results (Key Findings)

### Participant Images and Logs

Due in great part to the participants' enthusiasm for the variety of photo technologies available, this study achieved a wide spectrum of visual languages. Some participants requested to try multiple camera options. Repeat participants saw informative value in photographing specific experiences for dialysis communities (such as Camp Dorset trips or dialysis cruises). There were few instances of participants being overwhelmed or uninspired by camera technologies, and all but one who reported this opted to choose different camera systems and begin their photography periods anew.

Participants' images range across the more familiar as well as experimental. “Straight photography” in the style of documentary or snapshot appear, as do more poetic, diaristic images. Also present are an array of abstract and experimental imagery: images that are more emotive than descriptive, more affective than narrative, and visually and conceptually experimental in nature.

Some participants photographed daily, others in ad hoc ways; some pursued specific subjects to the exclusion of all else, whereas others were spontaneous in approaching



subject matter. Participants recorded loved ones and specific events, meaningful objects, dialysis treatment (dialysis units, medical equipment, and medication), and their own bodies to show changes from kidney disease and treatment. Some participants pursued abstracted evocations of emotions and experiences—both positive and negative. Some directed family members to act as photographer, capturing them as the subject. The study has initiated a participant community enthusiastic to provide varied, nuanced, and rich perspectives on (and engagements with) life on dialysis.

To date, we have collected more than 1600 images from 40 participants. We have also collected a series of participant logs that are similarly varied: some logs record the mechanics of how images were made, whereas others provide descriptive captions or record feelings that were experienced and/or reflected upon during the photographic act. Most of these logs are handwritten. Some participants using instant film chose to write on the photographs themselves, creating unexpected and expressive signatures on their image objects.

### Substudy Discussion

Substudy meetings provided a wealth of qualitative data. During the first meeting, participants were invited to discuss their immediate impressions of their images and their overall experiences as both photographers and viewers. Despite degrees of apprehension at the beginning of the study, many expressed participation to be a worthwhile effort. Many participants expressed that the study encouraged them to experience their surroundings anew and encouraged taking time to pause and “smell the roses”: to appreciate the positive aspects of life.

Participants' core values and objectives for the study were *mentorship* toward each other and especially toward newly diagnosed renal patients; *sharing experiences, positive messages, and attitudes* both in public and in treatment settings; *raising awareness* in the broader public around kidney disease prevention, organ donation, and *making renal disease treatments more visible*—therefore more recognizable and less jarring. One participant claimed the images could help newly diagnosed renal patients feel less anxious about their circumstances. Participants discussed how our peer-focused approach is valuable for predialysis communities and their families for fostering networks and shifting attitudes toward more positive outlooks. The images were described as informative and empowering for dialysis patients and their families, as well as health care providers and the general public.

In discussing how to contextualize and present images, general consensus was that semi-narrative lines of connection would be the most effective strategy. Participants suggested developing curated stories emphasizing patient activity and mobility: displays should focus on either one participant's images (images from an individual's life, activities, family, and home could be interspersed with images of their treatment) or broader themes that are shared across participants' images.

Substudy meetings were not audio recorded, but the research team recorded key words and phrases such as “dialysis doesn't stop people.” One participant expressed excitement that these images would help to combat a reaction they felt in their initial diagnosis: that they “would rather die than dialyze” because they assumed their quality of life on dialysis would be greatly reduced. Another stated that they may have made certain lifestyle changes had they known more about kidney disease when they were younger. Images of treatment were described as important for offsetting fear or bewilderment for those newly diagnosed and their families. Many images emphasized the importance of maintaining personal interests and interactions with others through dialysis treatment. Repeated and affirmative pairings of “challenge” with “opportunity” arose: “keeping things in perspective can be hard to do,” but “we're still here, we're still alive, and we're still having these moments.” Various expressions related to hope were shared: “Kidney disease is hopeless, but dialysis gives you hope again.”

Prioritizing how and where images should be disseminated, participants requested rotating mounted displays of images within dialysis units and suggested multimedia presentations be designed for unit iPads and televisions. They were less enthused about artistic exhibitions and publications. An Indigenous participant suggested images be used in Westmount's Aboriginal Resource Room and advised displays be made for regional Indigenous health centers and community health fairs. Substudy participants also advised expanding participant recruitment, promoting image awareness, and fostering community advocacy. Public spaces such as malls, medical centers, and doctors' offices were emphasized as important display sites for fostering public engagement. Participants stipulated that public displays required written context or even dialysis users who act as ambassadors to inform the public firsthand.

Throughout all substudy meetings, participants expressed the benefits of a web-based presence that might act as an accessible resource. Participants unilaterally expressed a desire to keep images off of social media, where potential anonymous harm could take place. Finally, participants reported qualitative benefits from participating in both the study and the substudy meetings: the meetings were useful community-building opportunities. Emphasizing the community-building aspect of the study, participants indicated that opportunities for peer discussion were deeply beneficial.

### Findings

This research study has proven to be an important refinement toward experiential learning and qualitative expression of individuals on dialysis. At this stage, researchers recognize the need to connect qualitative outcomes from this photo-based study with other qualitatively and quantitatively focused participant-centric studies. Furthermore, researchers

recognize the benefit of expanding the study perspective (with ethics approval) to include individuals at different points of their kidney disease journey (predialysis, home dialysis modalities, and kidney transplant recipients). This is discussed further in the “Conclusions and Next Steps” section.

Dialysis unit staff and the local Renal Patient and Family Advisory Council expressed interest in this study and invited researchers to present information at various stages. Feedback from these supportive groups was generally positive.

An additional vital outcome of this study relates to participant resilience: numerous participants discussed their initial willingness to take part in this study despite feeling hesitancy or uncertainty about the usefulness of their involvement (“What can my photographs offer?” “My life is not that interesting”). In both one-on-one and substudy meetings, participants expressed that their individual willingness to be vulnerable despite these hesitations contributed to their self-awareness and personal growth.

## Displays

Substudy discussions led to the production of large display banners incorporating images and logs. These banners were thematically designed to present cross sections of life on dialysis (family life, community, mobility and travel, food, holidays, hobbies, and participants’ experiences with experimental photography). Banners have been featured at World Kidney Day events, the Kidney Foundation’s Regional Meeting and local fundraising events, and LHSC’s Renal Education Day. We also produced a series of postcards featuring participant images and logs to share photographers’ insights. We displayed these postcards at LHSC Victoria Hospital, and a participant ambassador was on hand to describe their experiences with the study and answer general questions from the public.

Western University Schulich School of Medicine & Dentistry, in partnership with Lawson Health Research Institute, designed a multitiered interactive website about this ongoing study: *Bringing Healing Into Focus*. This website features participant statements and images, an in-depth interview with a study participant and context from the research team. The site has garnered high interaction from Western University, the general public, participants and their families, health care providers, researchers, and individuals within the medical industry. CTV London broadcast a general interest feature on the Photo Initiative, including an interview with a study participant.

Prior to the COVID-19 pandemic, the research team intended to organize image displays in public thoroughfares to reach and inform the general public. Substudy collaborators have requested that study participants be invited to act as

public advisors and speak to their own experiences as both dialysis patients and as photographers. These public initiatives have been paused.

## Limitations

Substudy focus groups discussed opportunities and limitations for using participant-generated visuals. Because not all participants opted to complete corresponding logs, how best to display personal imagery with adequate context remains both a challenge and an exciting open question. Related to this, the discussion of how to maintain the agency and potency of individual photographs without overcontextualizing (as indicated in our study priority) is challenging, as we seek to avoid falling into Photovoice habits that delimit the interpretive resonances of images.

## Conclusions and Next Steps

The success of this first study and the enthusiasm of participants have fostered an awareness of the need to explore the experiences of other individuals with chronic kidney disease with these research methods—including those not dialysis-dependent, those using home-based method of dialysis, and those who have opted for kidney transplantation. These expansions have been vetted and approved by the local research ethics board.

Members of the research team held exploratory meetings with Western University librarians and archivists to determine how a future study might incorporate a digital image archive searchable to researchers in related fields. At present, the research team has been contacted by researchers in close proximity to the project and we have shared images on an individual basis.

The research team anticipates following substudy suggestions for future action: incorporating images into educational material and conversation groups for newly diagnosed renal patients, directing images to promote organ education and organ donation, developing digital displays, and rotating visual displays in local dialysis units. Current health and safety protocols related to COVID-19 require the Photo Initiative to pause recruitment, substudy meetings, and any public displays, as well as to reassess immediate outputs for visuals.

This study model can be introduced to other renal units as long as there is an on-site researcher familiar with different camera systems and available to provide demos, field questions, and trouble-shoot technical difficulties.

## Ethics Approval and Consent to Participate

Approval from Western University’s Research Ethics Board (WREM, Project ID: 108649) was attained allowing for recruitment of participants from hemodialysis under care of London Health Sciences Centre.

### Consent for Publication

All authors read and approved the final version of this article. Study participants Elaine Hayter, Pamela Ireland, Jared McGregor, and Ann Tillmann were invited to read, edit, and provide crucial feedback for this article.

### Availability of Data and Materials

Materials for this study will remain with Dr Chris McIntyre and are available on request.

### Authors' Note

Western University, in partnership with Schulich School of Medicine & Dentistry and Lawson Health Research Institute, designed a multitiered interactive website about this ongoing study. Participant statements were prioritized. This website can be found here: <https://www.uwo.ca/renalcommunityphotoproject/>

### Author Contributions

R.S. and C.H. designed this study with input from C.M. and Dr Joy James. C.H. recruited participants and attained participant consent, disseminated camera technology, and collected photographic images from participants. R.S. scanned and archived photographic images. C.H. and R.S. organized substudy meetings with participants and their family members. All authors critically reviewed, revised, and approved the final article.

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