



Lessons learned from an observational study of patients with breast cancer: adaptations for remote implementation

Elizabeth A. Salerno^{1,2} · Courtney Harriss¹ · D. Carolina Andrade¹ · Lindsay L. Peterson^{2,3} · Christine M. Marx^{1,2} · Ryan P. Duncan^{4,5} · Jingqin Luo^{1,2} · Maura M. Kepper⁶ · Allison B. Anbari⁷ · Mary C. Politi^{1,2}

Received: 22 May 2024 / Accepted: 1 March 2025
© The Author(s) 2025

Abstract

Purpose There is increased demand for lifestyle interventions earlier on the cancer continuum (i.e., during curative-intent treatment). To address this need, researchers face unique challenges intervening in the short period of time after diagnosis, but before initiation of chemotherapy and/or surgery. During the peak of the COVID-19 pandemic, transitions to remote/digital platforms became both mandatory and immediate.

Methods This case study details the rapid transition to a remote/digital study embraced by our team as we recruited patients newly diagnosed with breast cancer to a pilot study. The pilot's purpose was to characterize the relationships between physical activity (PA) and cognitive and mental health during breast cancer treatment.

Results We reflect on the lessons learned during this pilot study with a particular focus on three emergent challenges: digital data collection, recruitment during active breast cancer treatment, and participant burden. We used a systematic implementation framework to track adaptations made to meet the evolving needs of patients and clinicians, while adhering to institutional protocols.

Conclusions This case study provides important insights into the delicate balance between patient, clinician, and institutional needs in the breast cancer setting, particularly when delivering digital interventions during treatment.

Implications for cancer survivors Careful attention should be paid to protocols for remote research to ensure that it is feasible, acceptable, and rigorous for all cancer survivors.

Keywords Cancer survivorship · Lessons learned · Case study · Remote delivery · Implementation science

✉ Elizabeth A. Salerno
e.salerno@wustl.edu

Courtney Harriss
courtney.harriss@wustl.edu

D. Carolina Andrade
andrased@wustl.edu

Lindsay L. Peterson
llpeterson@wustl.edu

Christine M. Marx
marxc@wustl.edu

Ryan P. Duncan
duncanr@wustl.edu

Jingqin Luo
jingqinluo@wustl.edu

Maura M. Kepper
kepperm@wustl.edu

Allison B. Anbari
anbaria@missouri.edu

Mary C. Politi
mpoliti@wustl.edu

¹ Division of Public Health Sciences, Department of Surgery, Washington University School of Medicine, 660 S. Euclid Ave, Campus, Box 8100, St. Louis, MO 63110, USA

² Alvin J. Siteman Cancer Center, Washington University School of Medicine, St. Louis, MO, USA

³ Division of Medical Oncology, Department of Medicine, Washington University School of Medicine, St. Louis, MO, USA

⁴ Program in Physical Therapy, Washington University School of Medicine, St. Louis, MO, USA

⁵ Department of Neurology, Washington University School of Medicine, St. Louis, MO, USA

⁶ Prevention Research Center, Brown School, Washington University, St. Louis, MO, USA

⁷ Sinclair School of Nursing, University of Missouri, Columbia, MO, USA

Introduction

Up to 4 million women currently live with a history of breast cancer in the USA [1]. The initial year after a breast cancer diagnosis is overwhelming, with some patients requiring over 20 clinical visits with physicians, 4.5 hours spent on visits to treat cancer-related symptoms, and tremendous financial burden [2–4]. Most patients with breast cancer experience declines in their mental health during treatment, with up to two-thirds of patients reporting symptoms of depression and anxiety [5]. Cancer-related cognitive decline is even more prevalent; 75% of patients with breast cancer report varying degrees of loss in mental acuity throughout their cancer experience [6]. These cognitive deficits can present as impaired verbal and visual memory, executive functioning, processing speed, and/or language and motor skills [7].

Engaging in physical activity (PA) is important to improve both physical and mental health post-diagnosis and might even prevent cancer recurrence [8–10]. Early intervention with PA prior to or during cancer treatment, or prehabilitation, can avoid or reduce the severity of treatment-related side effects, hospital length of stay, surgical complications, and care costs [11–14]. Recent evidence demonstrates the importance of PA for cognition among patients with breast cancer both during [15] and after treatment [16–18]. For example, we reported that meeting national PA guidelines at both the beginning and end of breast cancer chemotherapy was associated with better self-reported (e.g., perceived cognitive impairments) and objective (e.g., sustained attention) outcomes [15]. However, the time between diagnosis and treatment completion is complex; patients experience fluctuating cancer-related symptoms with a high frequency of clinical visits. This impacts intervention uptake [19] (e.g., patients are less likely to enroll when anxious or depressed) and efficacy [20] (e.g., patients are less likely to adhere when cognitively struggling). Prescribing PA during significant mental and cognitive burden has the potential to do more harm than good [19], leaving some patients frustrated and less likely to continue engaging in PA.

Thus, as we consider the design of PA interventions, it is crucial to consider the unique convergence of these mental and cognitive challenges to optimize intervention efficacy, feasibility, appropriateness, adherence, and enjoyment. To ensure that PA interventions delivered during breast cancer treatment are designed appropriately and sensitively, we conducted a longitudinal, observational study in 30 patients newly diagnosed with breast cancer. The purpose of the pilot study was to characterize the relationships between PA and cognitive and mental health during breast cancer treatment, explore the infrastructure necessary to support the

implementation of a healthcare-integrated PA intervention, and identify patients at highest risk of decline.

Recruitment for this pilot study coincided with the emerging Omicron variant of the novel coronavirus (SARS-CoV-2; COVID-19), resulting in adaptations to the study approach from in-person to fully remote. The use of implementation science frameworks, such as the Framework for Reporting Adaptations and Modifications—Expanded (FRAME) [21], is useful in characterizing adaptation to maintain study fidelity while working to close the gap between what works in ideal research settings and in end users' settings [22]. This report details barriers and lessons learned during this pilot study in three major areas: digital data collection, recruitment during active breast cancer treatment, and participant burden. We further discuss the process adaptations employed to address these barriers and characterize them using FRAME to meet the evolving patient needs and institutional protocols.

Original methods

Investigating Mental Health Physical Activity and Cognition during Treatment for Breast Cancer (IMPACT Breast Cancer) was originally designed to be conducted in-person, with all recruitment and data collection done during regular clinic visits. This study was funded in December 2021 through the pilot study mechanism of Washington University's Center for Perioperative Mental Health (P50MH122351), with plans to start recruitment at the beginning of 2022. The original methods for IMPACT Breast Cancer required that participants: (1) complete three health assessments during chemotherapy; (2) wear an accelerometer throughout chemotherapy; and (3) answer questions about their symptoms in the 6 days surrounding breast cancer surgery (i.e., ecological momentary assessments). The three health assessments were to be conducted at the beginning of chemotherapy (T1), halfway through chemotherapy (T2), and at the end of chemotherapy (T3). Each assessment consisted of a battery of questionnaires about different health outcomes and a series of cognitive tasks designed to measure executive function and processing speed. These assessments were originally designed to take place in clinic when patients arrived for their appointments. Cognitive function was designed to be measured using the NIH Toolbox as clinic staff would be present as proctors. Participants would then complete their questionnaires in person. Ecological momentary assessments were to consist of either a brief telephone call or text to a secure REDCap link.

Barriers were identified continuously throughout the study. Most were spontaneously reported by patients to the study team directly (e.g., patient brings up issue during scheduled study call), while the remaining were identified

by the study team during recruitment and data collection. The study coordinator noted each barrier in a working document, providing a detailed description and assigning a broad category (i.e., recruitment, patient experience). Barriers were then discussed by the study PI and coordinator to identify solutions. Complex issues were brought to the study team's multidisciplinary advisory board for further discussion. Upon study completion, this tracking document was reviewed carefully by the coordinator and PI to cluster barriers into three broad categories: digital data collection, recruitment during active breast cancer treatment, and participant burden. Solutions, or adaptations, were then tracked to the FRAME [21] by the PI with review from advisory board members.

Results

Barriers and solutions/adaptations are categorized by theme and further described below (see Table 1). We also detail adaptations to study processes using the FRAME [21] (see Table 2).

Theme #1: Digital data collection

On the first week of January 2022, principal investigators received an email about updated research policies due to the COVID-19 Omicron surge requesting that non-essential activities including for research be conducted virtually when

possible. Our study team convened with our advisory board to strategize protocol changes that would meet these new recommendations. Ultimately, we opted to change IMPACT to a fully remote study. This necessitated the purchase of research iPads with preloaded applications to mail to participants' homes and required the use of a cognitive function data collection tool that participants could self-administer. Our research team could no longer use the NIH Toolbox for cognitive testing, as that platform is designed to be proctored in person. We therefore established a data transfer agreement (DTA) with Digital Artefacts, the company that created BrainBaseline, an iPad application that allows for self-administered cognitive function testing. Further details on BrainBaseline methodology and measured cognitive domains in the context of breast cancer chemotherapy are published elsewhere [23]. Device acquisition and DTA establishment resulted in a four-month delay before new IMPACT procedures could begin. This process included mailing participants a research iPad for health assessment data collection (i.e., cognitive tasks and questionnaires), an accelerometer, and binder with a study welcome letter and detailed instructions. Participants were then scheduled for either a videoconference or phone orientation session to review the materials and answer questions prior to the start of data collection.

Several participants were uncomfortable and/or unfamiliar with videoconferencing, and the lack of visual aids to demonstrate during phone orientations limited the study team's ability to thoroughly explain the different iPad

Table 1 Identified barriers and solutions throughout the IMPACT Breast Cancer Study

Emergent themes			
	Digital data collection	Recruitment during active breast cancer treatment	Participant burden
Barriers	<ul style="list-style-type: none"> • COVID-19 Omicron variant necessitated remote delivery • Participant discomfort/unfamiliarity with technology • Lack of visual aids for study procedures 	<ul style="list-style-type: none"> • Working with only the division of medical oncology meant that patients who went straight to surgery were missed (i.e., adjuvant treatment) • Remote procedures due to COVID-19 made it difficult to establish clinician-researcher relationships 	<ul style="list-style-type: none"> • Participants reported different treatment-related side effects that affected study procedures • Wearing an accelerometer for the duration of chemotherapy was difficult for many and not feasible for some
Solutions (adaptations)	<ul style="list-style-type: none"> • Purchased research iPads for digital data collection • Incorporated orientation sessions to explain procedures • Met participants at chemotherapy infusions to assist with technology 	<ul style="list-style-type: none"> • Partnered with 13 different medical and surgical oncologists • Study team joined triage meetings within medical school, exposing study to wide variety of clinicians • Identified unique communication preferences for each clinician • Dedicated time to fostering clinician-researcher relationships • Coordinator ran weekly medical record reports • Assembled multidisciplinary advisory board to strategize creative recruitment methods 	<ul style="list-style-type: none"> • Purchased different wristbands for accelerometers to maximize participant comfort • Built flexibility into procedures to accommodate symptoms (e.g., encouraged participants to prioritize daytime accelerometer; made accelerometer tracking log optional) • Pared down instructions to reduce overwhelm

Table 2 Adaptations throughout the IMPACT Breast Cancer Study tracked to the Framework for Reporting Adaptations and Modifications—Expanded (FRAME) [21]

WHAT was adapted	NATURE of adaptation	Planned/Reactive	LEVEL of adaptation	HOW/BASIS of adaptation	GOAL of adaptation	THEME
Data collection—purchased iPads for remote delivery; identified cognition app (<i>context—format</i>)	<ul style="list-style-type: none"> Substituting 	Planned	Recipient	<ul style="list-style-type: none"> Existing policies (<i>sociopolitical</i>) Available resources (<i>organization/setting</i>) Access to resources (<i>recipient</i>) 	<ul style="list-style-type: none"> Increase reach or engagement Improve feasibility Improve fit with recipients Increase satisfaction 	Digital data collection
Onboarding—provided iPad orientations to aid patient use, technology comfort (<i>content</i>)	<ul style="list-style-type: none"> Changes in packaging or materials Adding elements 	Planned	Recipient	<ul style="list-style-type: none"> Literacy and education level (<i>recipient</i>) 	<ul style="list-style-type: none"> Increase retention Improve fit with recipients Increase satisfaction 	Digital data collection
Onboarding—met patients at infusions when teleconference orientations were not preferred (<i>context—format, setting</i>)	<ul style="list-style-type: none"> Loosening structure Substituting Tailoring/tweaking/refining 	Planned	Recipient	<ul style="list-style-type: none"> Location/accessibility (<i>organization</i>) Access to resources (<i>recipient</i>) 	<ul style="list-style-type: none"> Increase reach or engagement Improve feasibility Improve fit with recipients Increase satisfaction 	Digital data collection
Recruitment—modified staff communication based on provider preference; maximized patient-provider communication (<i>training; context—sensitive delivery</i>)	<ul style="list-style-type: none"> Tailoring/tweaking/refining 	Planned	Clinic/unit	<ul style="list-style-type: none"> Social context (<i>provider</i>) Preferences (<i>provider</i>) Cultural norms (<i>provider</i>) 	<ul style="list-style-type: none"> Increase reach or engagement Improve feasibility Improve fit with recipients 	Recruitment during active breast cancer treatment
General—assembled multidisciplinary advisory board (<i>training and evaluation</i>)	<ul style="list-style-type: none"> Adding elements Tailoring/tweaking/refining 	Planned	Organization	<ul style="list-style-type: none"> Available resources (<i>organization</i>) Social context (<i>organization</i>) 	<ul style="list-style-type: none"> Increase reach or engagement Improve feasibility Improve fit with recipients Improve effectiveness/outcomes 	Recruitment during active breast cancer treatment
Instructions—pared down accelerometer instructions for participant ease (<i>content</i>)	<ul style="list-style-type: none"> Tailoring/tweaking/refining Shortening/condensing 	Planned	Recipient	<ul style="list-style-type: none"> Comorbidity/multimorbidity (<i>recipient</i>) Physical/cognitive capacity (<i>recipient</i>) 	<ul style="list-style-type: none"> Improve feasibility Improve fit with recipients Increase satisfaction 	Participant burden
Data collection—built in flexibility as determined a priori (<i>context—other</i>)	<ul style="list-style-type: none"> Loosening structure 	Planned	Recipient	<ul style="list-style-type: none"> Comorbidity/Multimorbidity (<i>recipient</i>) 	<ul style="list-style-type: none"> Increase retention Improve fit with recipients Increase satisfaction 	Participant burden
Materials—purchased different wristbands for accelerometers to maximize patient comfort (<i>context—format</i>)	<ul style="list-style-type: none"> Changes in packaging or materials Substituting 	Planned	Recipient	<ul style="list-style-type: none"> Comorbidity/Multimorbidity (<i>recipient</i>) 	<ul style="list-style-type: none"> Increase retention Improve feasibility Improve fit with recipients Increase satisfaction 	Participant burden

applications. The lack of visual aids also impacted participants' ability to connect the iPad to their home internet (necessary for data transfer). Those who opted to engage in a phone orientation session to avoid technology issues also struggled through orientation, primarily due to study team members being unable to visually deliver instructions. Health assessment data collection on the iPad also required two different applications: (1) REDCap (to facilitate questionnaire data collection) and (2) BrainBaseline (to facilitate cognitive function data collection). The use of two applications meant that some participants only completed one or the other on their own, necessitating additional reminders and support from the study team. Some participants reported confusion and would complete some of the assessments twice or not at all, due to the different platforms for data collection.

Solutions/adaptations for theme #1

Once our team shifted all data collection from in-person to remote using iPads, our solutions to other tech-related challenges centered on how to maximize accessibility, study participation, and comfort/knowledge in using this technology. Future studies should strongly consider incorporating orientation sessions to walk participants through elements of the chosen digital platform. Unfortunately, this usually requires a form of technology (e.g., videoconferencing software), a paradoxical predicament. Our study team was fortunate that most participants appeared comfortable using technology during initial orientations, likely due to the world's shift to technology throughout the COVID-19 pandemic. One participant asked us to meet them at their first chemotherapy infusion to make things easier for them, a creative approach that soon became standard protocol for us. This was especially helpful for those participants who were not comfortable/familiar with using the videoconferencing software, as we quickly realized that phone orientations were too limiting. Our team instead conducted these orientation sessions during participants' first chemotherapy infusions. A team member would meet the participant in the infusion suite and go through all study materials in detail. One limitation to this solution is the inability to connect the iPad to participants' home internet; however, we included detailed instructions in their binders, walked the patient through the process in person, and followed up with phone calls the next day to confirm connection.

These in-person orientation meetings should take place in convenient locations for participants with the study team absorbing any transportation burden. While we were unable to solve the multiple-application challenge within the budget and timeframe of the pilot study, BrainBaseline does have the ability to combine surveys with cognitive function tasks, thus creating one platform for all data collection. We

recommend exploring the one-platform solution for future studies to avoid missing data as well as participant confusion, particularly when data collection is occurring across a long time frame (i.e., ≥ 8 weeks), with multiple concurrent clinical appointments, and when participants face significant cognitive burden (i.e., chemotherapy).

Access to technology has quickly become an important determinant of health, underscoring the need to consider digital health accessibility in the design of future studies [24]. While our pilot study mailed iPads to every participant, the provision of materials alone is inadequate. We recommend that researchers carefully consider participants' entire digital environment, ranging from digital literacy and self-efficacy to technology policy and algorithmic bias. This is particularly important as investigators seek to develop interventions that can be sustained beyond standard academic restraints (i.e., grant funding).

Theme #2: Recruitment during active breast cancer treatment

It became clear within the first month of recruitment that we would not be able to reach our desired sample within the study's timeframe if we kept to our original recruitment strategy of working with only medical oncologists; only three participants were successfully enrolled in the first 2 months of recruitment. The study PI and coordinator then began to attend weekly triage meetings within the school of medicine's division of oncology. This meeting brings together medical breast oncologists, clinical research coordinators, and PIs to discuss new trials, past and upcoming patient appointments, and summarize study accruals. The inclusion of IMPACT within the trials summary document allowed for clinical research coordinators to identify patients who may be eligible. However, given that the triage meetings were housed within medical oncology and not surgical oncology, several patients with adjuvant treatment regimens (treatment after, not before surgery) were not flagged until after surgery, meaning we missed a crucial window of time for data collection.

Solutions/adaptations for theme #2

Our team worked to establish partnerships with 13 different medical and surgical oncologists who served as "study champions" and permitted the study team to screen their clinics for eligible patients. These clinicians were individuals who were part of the institutional breast cancer team and responded to our outreach and expressed interest in supporting recruitment. These relationships were all unique, as clinicians had varying preferences for patient communication. Three primary communication methods emerged: (1) clinicians shared study brochures with every patient with

breast cancer who walked into the clinic and the study team called eligible patients after their clinic visit/receipt of brochure; (2) the study team identified eligible patients and shared those names with the clinicians' care teams, at which point the clinicians shared brochures; and (3) clinicians had one-on-one conversations (no script provided) with patients about the study before sharing patient names with the study team. Within several weeks of recruitment, this third method of patient–clinician conversations about the study emerged as the strongest means of successful enrollment. Due to its success, our study team increased procedural flexibility to accommodate each clinician and their unique workflows. This included the creation of a living document that housed each clinician's preference for communication, satellite site location for brochure drop-offs, and updated notes to make it easier for clinicians to share study information with patients and maximize enrollment.

The study coordinator also ran weekly electronic health record reports to further identify eligible patients who may not have been flagged through the above methods, focusing specifically on operative dates to identify adjuvant patients prior to surgery. Using multiple channels to identify eligible patients increased enrollment dramatically; eight participants were enrolled in the next 2 months, which more than doubled our recruitment rate. Building these researcher–clinician relationships took time, commitment, and careful consideration of the daily demands that clinicians and their care teams face. The study team assumed as much of the communication burden as possible to alleviate pressure on clinical workflow, which necessitated dedication from the study coordinator. We also assembled a multidisciplinary advisory board that strategized creative methods for working within the healthcare system, from both the clinician and patient perspective. Board members ensured that partners from all domains and specialties were represented when making important study-related decisions.

Theme #3: Participant burden

Active cancer treatment is dynamic with respect to dose, timing, and symptoms [25]. As a result, several challenges arose related to participant burden. Many patients reported several serious treatment side effects, including trouble sleeping, fatigue, gastrointestinal distress, bloating, peripheral neuropathy, nausea, and compounded symptoms due to infection with COVID-19. These symptoms affected participants' ability to wear their accelerometers for the duration of chemotherapy. This accelerometer wear time was novel to IMPACT; most accelerometry data collection requires a minimum of 3 days [26]. While we were interested in the patterns of change in PA throughout chemotherapy, it became apparent that this brought too much burden to

participants; the average length of chemotherapy for patients enrolled in IMPACT was 14.8 weeks. Many participants also reported a great deal of overwhelm throughout treatment which affected their ability to complete study activities.

Solutions/adaptations #3

While no significant changes could be made to study procedures to reduce the side effects of chemotherapy, we adapted our protocol to be more flexible in accommodating these symptoms. Several participants noted that the standard accelerometer wristband for nighttime wear was uncomfortable, scratchy, and disturbed their sleep. Our study team then tested several commercially available wristbands with soft and flexible fabric before settling on a new wristband to purchase and send to all participants. We further encouraged participants to avoid wearing the accelerometer at night if it interrupted their sleep. For participants who reported gastrointestinal symptoms that were exacerbated by wearing the accelerometer around their waist during the day, we encouraged participants to try different wear techniques that eliminated the band (e.g., monitor in pants pocket, safety pin monitor pouch to pants) or to skip a day when symptoms were especially incapacitating. To further reduce burden, we made the accelerometer logs (e.g., tracking of wear time) optional for participants. Relaxing some of the accelerometer requirements reduced participant burden and maximized our chances of obtaining the primary outcome data we sought (i.e., average daily PA).

One solution our team employed was frequent meetings with our advisory board in the early stages of the study to gather perspectives in how much information should be delivered to patients, at what time, and in what medium. Insights from patient advocates, staff coordinators, researchers, and oncologists helped reduce unnecessary participant burden in ways that preserved data integrity. For example, we pared down a multi-page instruction pamphlet on wearing an accelerometer to a one-page info sheet with key details thanks to crucial feedback from patient advocates. We then provided a frequently asked questions document about the accelerometer in the event participants were curious to know more. This practice allowed overwhelmed patients to focus on the basic instructions only, while also providing additional details for those patients who may have wanted more information and context.

Discussion

Research participation during active cancer treatment can be overwhelming for patients; however, research suggests that this is also a crucial time for intervention to mitigate treatment-related health declines. This balance clearly

necessitates thoughtfulness from the study team. When using remote platforms for data collection, teams must consider the confluence of technology burden/uptake, emerging treatment-related symptoms, and recruitment during a highly demanding time when there may be limited in-person interaction with the study team. Herein, we presented three main challenges (and solutions) that arose during our longitudinal, observational study in 30 patients during breast cancer treatment: (1) digital data collection, (2) recruitment during active breast cancer treatment, and (3) participant burden.

The current study was designed to reduce many of the previously reported burdens during active breast cancer treatment, including travel constraints and multiple appointments; however, research participation of any kind adds to patients' stress during treatment. Researchers should carefully weigh the amount of data to be collected, timing of said data collection, and mental load required by both participants and researchers to manage participation when designing remotely delivered research studies. There must be a balance between the provision of instructions and overwhelming participants with too much information. Future studies in the breast cancer setting should be particularly mindful of treatment toxicities and how symptomology can significantly impact adherence to study procedures. Building flexibility into procedures is imperative, with an eye toward triaging data collection *a priori*. For example, our study team prioritized daytime wear of the accelerometer as much as possible while all other elements could be relaxed as needed. This flexibility allowed participants with significant treatment side effects to participate meaningfully without needing to complete all procedures, while those with minimal side effects were able to fully engage. This individualized approach is a theme of cancer research and should continue to be prioritized in future studies.

It is important to note that most of the adaptations made to this study's implementation were process-related. That is, the content of the study remained largely the same while our procedures were adapted to accommodate patient, clinic, and institution needs and preferences. The field of implementation science provides systematic frameworks through which we can adapt evidence-based interventions to maintain efficacy while working to close the gap between what works in ideal research settings and in patients' community settings [22]. The use of the FRAME [25, 26] enabled us to better conceptualize how our adaptations led to more effective engagement, acceptability, and delivery of our study procedures. As detailed in Table 2, it is clear that most of these adaptations were contextual (i.e., changes to how the study was delivered, study setting, study personnel) and were comprised of loosening the structures and tailoring, rewording, and refining materials. It is important to note that these modifications left the study principles and techniques largely intact, underscoring that fidelity can indeed

be achieved even in the face of significant implementation barriers.

These barriers and our identified solutions highlighted several themes for future directions for research endeavors in this space, and further underscore the utility of implementation science frameworks for ensuring that these solutions can be sustained in the long-term.

1. **Flexibility.** There are many competing priorities in a patient's life when diagnosed with a physically and emotionally burdensome illness such as breast cancer, which can result in a high degree of overwhelm and psychological distress. This burden can be exacerbated in academic medical centers when patients may be approached to participate in a litany of research studies. To reduce distress, research teams should consider relaxing rigid data collection procedures. Offering a choice (i.e., in-person or remote) is one approach that not only meets patients where they are, but also offers a way of returning control and power to patients who have been stripped of it by their diagnosis and ensuing treatment regimens. To maintain scientific rigor, these choices and flexibilities should be systematically tracked for later analysis. Flexibility is not only limited to engagement with participants; it also applies to developing partnerships with clinical recruitment sources (see Table 1). One size will never fit all physicians and their care teams, and researchers would do well to flex their recruitment approaches to fit within the overarching structures of clinic workflow.
2. **Proactive partnership.** Researchers are skilled at following evidence-based science and developing rigorous procedures to answer *a priori* hypotheses; however, very few investigators have the lived experience of their participants. Study teams should consider their end users at the very beginning of every study. This includes acknowledging the wide gap between researcher and participant, engaging patient advocate(s), and/or piloting and refining materials throughout the study period. Not only is this practice respectful, but it also supports high levels of adherence by maximizing usability and value. This is a core principle of designing for dissemination, implementation, and sustainability (D4DIS) [27–29] which can support translation of study findings into practice. Partnership also applies to participants' home lives; many noted that their adult children would assist them with the IMPACT iPad, highlighting a potential opportunity for future dyadic or family-based studies grounded in partnership.
3. **Creativity.** The COVID-19 pandemic accelerated a movement to remote delivery of many aspects of healthcare and research. While this has resulted in increased acceptability and usability of certain technologies (i.e.,

videoconference) [30, 31], researchers have had to be creative in adapting procedures from in-person to remote. This creativity is not only integral to continuing research, but it can also lead to new processes [32, 33].

Our team was not the first to adapt its procedures due to COVID-19 and will not be the last needing to quickly pivot. Previous studies have noted the importance of being “resilient” in these adaptations [34], a key theme that our findings support. Successful study implementation is clearly reliant on strong partnerships and understanding and addressing the specific needs of participants, with a healthy dose of humility. Future research should systematically explore the sustainability of identified and implemented adaptations (i.e., using mixed methods, follow-up periods) to ensure that our research can persist long after the traditional grant life cycle. This work should further explore the extent to which further adaptation is necessary, so that our research adequately addresses the needs of varying populations [35, 36]. As research continues to rely more heavily on technology, digital health must remain a top priority in study protocol design to ensure that all individuals have a fair and just opportunity to participate and be as healthy as possible.

Acknowledgements This study was funded by the National Institute of Mental Health (grant number P50MH122351).

Author contribution All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Elizabeth Salerno and Courtney Harriss. The first draft of the manuscript was written by Elizabeth Salerno, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding This study was funded by the National Institute of Mental Health (Grant number P50MH122351).

Data availability No datasets were generated or analysed during the current study.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Protocol Review and Monitoring Committee (PRMC) and Washington University Institutional Review Board (IRB) (#202201163).

Consent to participate Informed consent was obtained from all individual participants included in the IMPACT Breast Cancer Study.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

Open Access This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit

to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. DeSantis CE et al (2019) Breast cancer statistics, 2019. *CA Cancer J Clin* 69(6):438–451. <https://doi.org/10.3322/caac.21583>
2. Dean LT et al (2019) ‘It still affects our economic situation’: long-term economic burden of breast cancer and lymphedema. *Support Care Cancer* 27(5):1697–1708. <https://doi.org/10.1007/s00520-018-4418-4>
3. Henry DH, Viswanathan HN, Elkin EP, Traina S, Wade S, Cella D (2008) Symptoms and treatment burden associated with cancer treatment: results from a cross-sectional national survey in the U.S. *Support Care Cancer* 16(7):791–801. <https://doi.org/10.1007/S00520-007-0380-2>
4. Sav A, McMillan SS, Akosile A (2021) Burden of treatment among elderly patients with cancer: a scoping review. *Healthc* 9(5):612. <https://doi.org/10.3390/HEALTHCARE9050612>
5. Maass SWMC, Roorda C, Berendsen AJ, Verhaak PFM, De Bock GH (2015) The prevalence of long-term symptoms of depression and anxiety after breast cancer treatment: a systematic review. *Maturitas* 82(1):100–108. <https://doi.org/10.1016/J.MATURITAS.2015.04.010>
6. Janelins MC, Kesler SR, Ahles TA, and Morrow GR (2014) “Prevalence, mechanisms, and management of cancer-related cognitive impairment.” *Int Rev. Psychiatry* 26(1): 102–113 <https://doi.org/10.3109/09540261.2013.864260>
7. Raffa RB (2010) “Is a picture worth a thousand (forgotten) words?: neuroimaging evidence for the cognitive deficits in ‘chemo-fog’/‘chemo-brain,’” *Journal of Clinical Pharmacy and Therapeutics*, vol. 35, no. 1. John Wiley & Sons, Ltd (10.1111) 1–9 <https://doi.org/10.1111/j.1365-2710.2009.01044.x>.
8. Schmitz KH et al (2019) Exercise is medicine in oncology: engaging clinicians to help patients move through cancer. *CA Cancer J Clin* 69(6):468–484. <https://doi.org/10.3322/caac.21579>
9. Patel AV et al (2019) American College of Sports Medicine Roundtable Report on physical activity, sedentary behavior, and cancer prevention and control. *Med Sci Sports Exerc* 51(11):2391–2402. <https://doi.org/10.1249/MSS.00000000000002117>
10. Campbell KL et al (2019) Exercise guidelines for cancer survivors: consensus statement from International Multidisciplinary Roundtable. *Med Sci Sports Exerc* 51(11):2375–2390. <https://doi.org/10.1249/MSS.00000000000002116>
11. Stout NL, Silver JK, Baima J, Knowlton SE, Hu X (2020) “Prehabilitation: an emerging standard in exercise oncology”, in *Exercise Oncology*. Springer International Publishing, Cham, pp 111–143
12. Silver JK, Baima J (2013) Cancer prehabilitation. *Am J Phys Med Rehabil* 92(8):715–727. <https://doi.org/10.1097/PHM.0b013e31829b4afe>

13. Silver JK (2015) Cancer prehabilitation and its role in improving health outcomes and reducing health care costs. *Semin Oncol Nurs* 31(1):13–30. <https://doi.org/10.1016/j.soncn.2014.11.003>
14. Carli F, Gillis C, Scheede-Bergdahl C (2017) Promoting a culture of prehabilitation for the surgical cancer patient. *Acta Oncologica* 56(2):128–133. <https://doi.org/10.1080/0284186X.2016.1266081>
15. Salerno EA et al (2021) Physical activity patterns and relationships with cognitive function in patients with breast cancer before, during, and after chemotherapy in a prospective, nationwide study. *Journal of Clinical Oncology* 39(29):3283–3292. <https://doi.org/10.1200/JCO.20.03514>
16. Salerno EA, Rowland K, Kramer AF, McAuley E (2019) Acute aerobic exercise effects on cognitive function in breast cancer survivors: a randomized crossover trial. *BMC Cancer* 19(1):1–9
17. Salerno EA, Rowland K, Hillman CH, Trinh L, Kramer AF, McAuley E (2020) Dose-response effects of acute aerobic exercise duration on cognitive function in patients with breast cancer: a randomized crossover trial. *Front Psychol* 11:1500. <https://doi.org/10.3389/fpsyg.2020.01500>
18. Ehlers DK et al (2018) Replacing sedentary time with physical activity or sleep: effects on cancer-related cognitive impairment in breast cancer survivors. *BMC Cancer* 18(1):1–11
19. van Waart H, van Harten WH, Buffart LM, Sonke GS, Stuiver MM, Aaronson NK (2016) Why do patients choose (not) to participate in an exercise trial during adjuvant chemotherapy for breast cancer? *Psychooncology* 25(8):964–970. <https://doi.org/10.1002/pon.3936>
20. McAuley E et al (2011) Self-regulatory processes and exercise adherence in older adults: executive function and self-efficacy effects. *Am J Prev Med* 41(3):284–290. <https://doi.org/10.1016/j.amepre.2011.04.014>
21. Wiltsey Stirman S, Baumann AA, and Miller CJ (2019) “The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions.” 14(1) <https://doi.org/10.1186/s13012-019-0898-y>.
22. Kessler R, Glasgow RE (2011) A proposal to speed translation of healthcare research into practice: dramatic change is needed. *Am J Prev Med* 40(6):637–644. <https://doi.org/10.1016/j.amepre.2011.02.023>
23. Salerno EA et al (2023) Exercise during chemotherapy to prevent breast cancer-related cognitive decline: protocol for a pilot randomized controlled trial. *Front Cogn* 2:1289415. <https://doi.org/10.3389/FCOGN.2023.1289415>
24. Richardson S, Lawrence K, Schoenthaler AM, and Mann D (2022) “A framework for digital health equity,” *npj Digit. Med.* 2022 51, vol. 5(1)pp. 1–6 <https://doi.org/10.1038/s41746-022-00663-0>.
25. Gandhi TK et al (2005) Medication safety in the ambulatory chemotherapy setting. *Cancer* 104(11):2477–2483. <https://doi.org/10.1002/CNCR.21442>
26. Choi L, Liu Z, Matthews CE, Buchowski MS (2011) Validation of accelerometer wear and nonwear time classification algorithm. *Med Sci Sports Exerc* 43(2):357. <https://doi.org/10.1249/MSS.0B013E3181ED61A3>
27. Stirman SW, Baumann AA, Miller CJ (2019) The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions. *Implement Sci* 14(1):58. <https://doi.org/10.1186/s13012-019-0898-y>
28. Walsh-Bailey C et al (2021) A pilot study comparing tools for tracking implementation strategies and treatment adaptations. *Implementation Research and Practice* 2:263348952110160. <https://doi.org/10.1177/26334895211016028>
29. Brownson RC, Jacobs JA, Tabak RG, Hoehner CM, Stamatakis KA (2013) Designing for dissemination among public health researchers: findings from a national survey in the United States. *American Journal of Public Health* 103(9):1693–1699. <https://doi.org/10.2105/AJPH.2012.301165>
30. Brownson RC, Colditz GA, and Proctor EK (2012) *Dissemination and implementation research in health: translating science to practice.*
31. Glasgow RE, Emmons KM (2007) How can we increase translation of research into practice? Types of Evidence Needed. *Annual Review of Public Health* 28:413–433. <https://doi.org/10.1146/ANNUREV.PUBLHEALTH.28.021406.144145>
32. Gothe NP, Erlenbach E (2021) Feasibility of a yoga, aerobic and stretching-toning exercise program for adult cancer survivors: the STAYFit trial. *J Cancer Surviv* 2021:1–10. <https://doi.org/10.1007/S11764-021-01101-Y>
33. Torous J, Myrick KJ, Rauseo-Ricupero N, Firth J (2020) Digital mental health and COVID-19: using technology today to accelerate the curve on access and quality tomorrow. *JMIR Mental Health* 7(3):e18848. <https://doi.org/10.2196/18848>
34. Rahman SA, Tuckerman L, Vorley T, and Gherhes C (2021) “Resilient research in the field: insights and lessons from adapting qualitative research projects during the COVID-19 pandemic,” *Int. J. Qual. Methods* 20 https://doi.org/10.1177/16094069211016106/ASSET/IMAGES/LARGE/10.1177_16094069211016106-FIG1.JPEG.
35. Shelton RC, Cooper BR, and Stirman SW (2018) “The sustainability of evidence-based interventions and practices in public health and health care,” in *Annual Review of Public Health*, 39 <https://doi.org/10.1146/annurev-publhealth-040617-014731>
36. Braveman P, Arkin E, Orleans T, Proctor D, Acker J, Plough A (2018) What is health equity? *Behav Sci Policy* 4(1):1–14

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.