SURVEILLANCE AND REHABILITATION FOR BREAST CANCER-RELATED UPPER-BODY ISSUES

by

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Abstract

There is a growing population of breast cancer survivors world-wide due to an ageing population, improved early detection, treatment advances and longer survival. Breast cancer survivors experience persistent upper-body issues following surgery and adjuvant treatment. Physical rehabilitation is known to improve outcomes in upper-body functioning. Strategies to improve reach and access of physical rehabilitation interventions and early detection of upper-body issues are needed to prevent the development of chronic issues.

This dissertation aims to develop and test new delivery approaches to surveillance and physical rehabilitation by employing a variety of research methodologies. The first study was a development and feasibility study of the Breast Cancer Online Rehabilitation (BRECOR) program, consisting of a clinical assessment tool, a pamphlet and website to inform and support 12-week self-managed upper-body rehabilitation. This program was found to be feasible for use in community-based centres with preliminary evidence of efficacy. The second study was cross-sectional and tested the reliability and validity of self-measured arm circumference, as well as attitudes towards self-managed surveillance for breast cancer-related lymphedema. The third study was prospective and tested the feasibility and reliability of self-managed surveillance for upper-body issues as part of a hospital-based program. The fourth study aimed to understand experiences and preferences for surveillance and rehabilitation services using qualitative research methods among breast cancer survivors, rehabilitation professionals and breast surgeons from across British Columbia. Participants reported that current services did not enable early detection and were in need of revamping to increase equity of care. Suggestions included providing multimodal self-management resources.

In summary, these studies propose new delivery approaches to enable timely and support evidence-based upper-body rehabilitation. The studies lay the groundwork for future randomized controlled trials to determine the magnitude of the effect that self-managed surveillance and rehabilitation may have on the prevalence of chronic breast cancer-related upper-body issues.

Lay Summary

Many women live with pain or limitations in upper-body function after treatment for breast cancer, partly because they do not receive sufficient rehabilitation due to barriers around access and cost of treatment. The research projects in this dissertation are focused on developing innovative approaches to enable early detection and access to evidence-based rehabilitation. The first study demonstrated that online and printed resources can assist women in performing relevant upper-body rehabilitation at home. Participants improved their upper-body functioning and reported benefit from the program. The second and third studies demonstrated that, with new educational resources, women can monitor themselves for issues accurately. Self-monitoring was of interest to most women and reported to be easy to do. Finally, the fourth study provided insight into the experiences among women and healthcare professionals on current rehabilitation services and ideas for ways to promote early detection and access to rehabilitation.

Preface

This statement confirms that the work presented in this dissertation was conceived, conducted and written by Bolette Skjødt Rafn (BSR). The co-authors of the manuscripts, including Dr. Kristin Campbell (KC), Dr. Julie Midtgaard (JM), Dr. Pat Camp (PC), Carina Nees (CN), Jette Vibe-Petersen (JVP), Dr. Margaret McNeely (MM), and Chiara Singh (CS) made contributions commensurate with supervisory committee or co-author duties.

The research in Chapter 2 was conducted under the University of British Columbia Clinical Research Ethics Board (H15-03270) and the Danish Ethics Board (H-15017482). The research was conducted in Denmark. BSR established a collaboration with the Copenhagen Center for Cancer and Health (CCCH) to undertake this work. In close collaboration with CN and JVP located at CCCH, BSR developed and tested the usability of the BRECOR resources. With substantive input from KC, BSR developed the research question and protocol for the feasibility study. CN was responsible for recruiting participants and collecting the data. BSR was responsible for data analysis and writing the manuscript. KC, JM, PC provided scientific input throughout the process, as well as editing and approval of the final manuscript. Chapter 2 is accepted for publication:

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The research in Chapter 3 was conducted under the University of British Columbia Clinical Research Ethics Board (H16-00961). BSR conceived and designed the research question with assistance from KC and MM, and developed the study material (written and video material). BSR prepared the application for the research grant that funded this study with substantive input from KC. BSR was responsible for recruiting participants, data collection, conducted the data analysis, and was responsible for interpretation. BSR wrote the manuscript with scientific input, editing and final approval of the manuscript from KC, JM, PC, and MM. Chapter 3 has been published:

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The research in Chapter 4 was conducted under the University of British Columbia Clinical Research Ethics Board (H17-01992). The research was conducted at Surrey Memorial Hospital, British Columbia. BSR was responsible for developing the research question and design with input from CS and KC. CS was responsible for recruiting participants and collected the data in collaboration with BSR. BSR analyzed the data and drafted the manuscript with input and approval of the final manuscript by KC, CS, JM, PC, and MM. Chapter 4 has been submitted for publication, and is currently under review:

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The research in Chapter 5 was conducted under the University of British Columbia Behavioural Research Ethics Board (H17-00928). With input from JM and KC, BSR conceived the research question, designed the research protocol and created the focus group guide. BSR prepared the application for the research grant that funded this study with substantive input from KC. BSR recruited participants and facilitated all focus groups. With support from JM, BSR coded and analyzed all data and wrote the manuscript. KC, JM and PC provided scientific contribution to interpretation of the data and revision of the chapter. Chapter 5 has been submitted for publication:

Rafn BS, Midtgaard J, Camp PG, Campbell KL. Room for improvement of breast cancer rehabilitation services: A focus group study of survivors' and professionals' experiences and preferences for rehabilitation care delivery (*Submitted for publication*).

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List of Abbreviations

Abd:	abduction
ADL:	activities of daily living
ALND:	axillary lymph node dissection
BC:	British Columbia
BCRL:	breast cancer-related lymphedema
BCS(s):	breast cancer survivor(s)
BMI:	body mass index
BRECOR:	breast cancer online rehabilitation
BS(s):	breast surgeon(s)
CDT:	complex decongestive therapy
CI:	confidence interval
CIR_{self_home}:	self-measurement of arm circumference at home
CIR_{self_lab}:	self-measurement of arm circumference at laboratory
CIR_{ther}:	therapist-measurement of arm circumference
Ext. rot:	external rotation
Flex:	flexion
HA:	health authority
HBM:	Health Belief Model
IBR:	immediate breast reconstruction
ICF:	International Classification of Functioning
ICC:	intra-class correlation coefficient

Int. rot:	internal rotation
MCID:	minimal clinically important difference
MDC:	minimal detectable change
MLD:	manual lymph drainage
Nm:	newton meter
P:	participant
PT(s):	physical therapist(s)
r:	Pearson's correlation
RCT(s):	randomized controlled trial(s)
ROM:	range of motion
RP(s):	rehabilitation professional(s)
SD:	standard deviation
SEM:	standard error of measurement
SLN:	sentinel lymph node
SLNB:	sentinel lymph node biopsy
SMH:	Surrey Memorial Hospital
SRM:	Self-Regulation Model
TPB:	Theory of Planned Behaviour
UBC:	University of British Columbia
VOL_{per}:	arm volume obtained from perometry
VOL_{self_home}:	arm volume calculated from the self-measurements at home
VOL_{self_lab}:	arm volume calculated from the self-measurements at the laboratory
VOL_{ther}:	arm volume calculated from the therapist-measurements

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Dedication

To the breast cancer survivors who contributed to this work

Chapter 1: Introduction

1.1 Breast Cancer in Canada

Breast cancer is the most common malignancy among women worldwide[1] with a yearly incidence of 25,700 in Canada[2]. Ten years after diagnosis for breast cancer, 82% of Canadian women are still alive and survival rates are expected to continue to increase due to a combination of early detection via increased mammography screening[3] and the use of more effective therapies following breast cancer surgery[4]. Breast cancer treatment, however, is associated with a number of physical sequelae including limitations in upper-body function, muscle strength, range of motion (ROM), pain, tightness or lymphedema, together referred to as breast cancer-related upper-body issues. These issues are prevalent worldwide and significantly restrict breast cancer survivors (BCSs) ability to participate in work[5] and recreational activities[6], alter body image and feelings of femininity[7] and reduce health-related quality of life[8].

1.2 Breast Cancer and its Treatment

The standard treatments for primary breast cancer include surgery, radiation therapy, chemotherapy, and endocrine (hormonal) therapy, which can be delivered alone or in combination. Breast cancer treatment decisions are based partly on stage of the cancer at initial diagnosis but primarily on tumour size, lymph node status, receptor status in the tumour tissue, menopausal status, and the age and general health of the patient[9].

1.2.1 Breast Cancer Surgery

There have been several important developments in the surgical management of breast cancer including new techniques for tumour resection, reconstructive surgery, lymph node assessment, cosmetic surgery[10] and improved surgical instruments[11]. Generally, treatment is moving from a "better safe than sorry" approach towards a less extensive or even an omitted axillary surgery in selected patients[12].

Mastectomy is the surgical removal of the whole breast. Mastectomy is indicated in patients who have received neo-adjuvant (pre-surgery) chemotherapy with minimal tumour response, or in patients "who have received previous moderate- or high-dose radiation to the breast or chest wall; are pregnant and would require radiation during pregnancy; have diffuse suspicious or malignant-appearing micro-calcifications on mammography; have widespread disease that cannot be incorporated with local excision through a single incision with a satisfactory cosmetic result; or have positive pathologic margins"[13 page 160].

Lumpectomy is the surgical removal of the tumour and a small amount of the surrounding tissue. Breast-conserving therapy (lumpectomy followed by radiotherapy) is standard treatment for small tumours and is associated with better disease-free survival and less severe upper-body issues than mastectomy[14,15]. In a cohort of 1.2 million American survivors of early-stage breast cancer who were eligible for lumpectomy, 35.5% underwent mastectomy surgery, while the remaining 64.5% underwent lumpectomy surgery[16]. In the same cohort, rates of prophylactic bilateral mastectomy for unilateral cancer increased from 1.9% in 1998 to 11.2% in 2011[16]. Of note, compared to lumpectomy, mastectomy negatively impacts shoulder ROM due to greater soft tissue loss in the axillary and pectoral areas following the surgery[17].

Today, approximately 22% of women undergoing mastectomy choose to have immediate breast reconstruction (IBR) surgery, which is a doubling compared to the 1990s[18,19]. This is partly explained by the increasing rate of mastectomies performed each year, also among women with early-stage breast cancer[20]. In particular, younger women with lower cancer stage frequently choose IBR. Until recently, there has been little data on the association of IBR with the development of breast cancer-related lymphedema (BCRL) post-mastectomy. New evidence suggests that IBR may be associated with a reduced risk of BCRL[21,22]. A prospective study of 891 women with breast cancer demonstrated a lower incidence of BCRL after IBR with implant (5.13%, 95% confidence interval (CI) 3.50; 7.49%) compared to no reconstruction (26.66%, 95% CI 20.38; 34.43%) after controlling for risk factors (i.e., body mass index (BMI), radiation therapy, number of lymph nodes dissected)[23]. As such, the risk for BCRL was greatly reduced (hazard ratio 0.43, $p < 0.01$) after IBR. In this study, BCRL was defined as a 10% bodyweight-adjusted increase in volume from pre-surgery measured by perometry[23]. Similar findings are reported by other studies of IBR[24] and delayed breast reconstruction[25]. Recent work has compared different IBR modalities, and report lower 2-year incidence of BCRL among 429 BCSs following autologous (tissue from another body part) reconstruction (4.2%) versus implant (9.3%)[26]. In contrast, a recently published cohort of 622 women with 10 years follow-up demonstrated no difference in risk for BCRL in women with immediate, delayed or no reconstruction[27]. Possible explanations for the potential protective effect of IBR on BCRL risk include that patients undergoing IBR typically have skin sparing mastectomies, which preserves more of the skin and therefore lymphatic vessels under the skin. Alternatively, patients without reconstruction undergo more resection of breast and axillary skin for optimal healing and cosmetics. As a consequence, patients with no reconstruction may experience tissue adhesion,

fibrosis, and contracture of the breast skin, chest wall, and axilla, resulting in obstructed lymphatic flow and possibly BCRL development[21]. Specific to other types of upper-body issues, a recent case-control study demonstrated no difference in pain, restricted shoulder ROM, muscle strength or patient-reported shoulder function between women with (n = 30) and without (n = 30) IBR at 2 years post-surgery[28].

1.2.1.1 Lymph Node Dissection

Axillary lymph nodes are the most common site of breast cancer metastasis[29]. The standard pre-operative evaluation consists of a physical examination and axillary ultrasound to determine lymph node staging. If negative, then the patient is considered node negative and a sentinel lymph node biopsy (SLNB) is performed to confirm the sentinel lymph node (SLN) status. SLNB was developed as a minimally invasive alternative to the traditional axillary lymph node dissection (ALND), as metastasis of the primary breast tumour will almost always occur in the first sentinel node to receive the lymph from the involved area of the primary tumour. If the SLN is cancer negative other axillary nodes are assumed to be clear of cancer, and ALND is not recommended. As such, a positive SLNB would normally be followed by completion of ALND. A 2010 American cohort of 96,656 BCSs reported that at diagnosis, 28% had positive SLN, of whom 16.4% underwent SLNB and the remaining 83.6% underwent ALND[30].

Lately there has been a decline in the indication of completion of ALND. Findings from several randomized trials suggest that for patients with positive SLN, ALND is no longer indicated as breast surgery and adjuvant radiation therapy provide similar cancer control while importantly having lower incidence of BCRL[31–34]. Further, safety of omitting SLNB and radiation therapy in patients with non-invasive breast cancer (in situ) without lymph node

involvement has recently been demonstrated[35,36]. The rationale behind this derives from the aforementioned studies[32,33], which demonstrated that residual lymph node metastases did not result in worse recurrence or survival rates. The experience of upper-body issues is directly influenced by the number of lymph nodes removed, the extent of breast surgery and radiation therapy in the axilla[37]. Thus, the prevalence of upper-body issues, and BCRL in particular, is likely to decrease in the coming years due to omitting ALND and even SLNB in patients with early-stage breast cancer.

1.3 Breast Cancer-related Upper-body Issues

For the purposes of this doctoral thesis, upper-body issues are defined as one or a combination of the following impairments: 1) limited shoulder range of motion (ROM), 2) pain or tightness in the upper-body, 3) reduced upper-body muscle strength, 4) functional limitations in performing activities involving the upper-body, or 5) breast cancer-related lymphedema. The following paragraphs will outline the mechanistic causes, definitions and prevalence rates.

1.3.1 Mechanistic Causes of Impaired Shoulder Range of Motion, Muscle Strength, Pain and Tightness

Breast pain, reduced muscular strength, and limited shoulder ROM are consequences of the fact that treatment for breast cancer directly involves the neuro-musculoskeletal tissues in the shoulder girdle regions (pectoral and axillary regions). Muscle atrophy and weakness of the shoulder is common among breast cancer survivors[38,39] and will affect the timing and activation of the muscles and decrease the muscular control of the shoulder girdle joints (glenohumeral, scapula-thoracic, acromioclavicular and sternoclavicular joints)[40]. Even among BCSs without

upper-body issues, the scapula-thoracic movement has been shown to be altered, likely caused by altered motor control and use of the affected arm[39,41]. This may subsequently increase the risk of impingement of soft tissues in the sub-acromial space (tendons of m. supraspinatus and biceps brachialis) when performing overhead activities and trigger the development of shoulder pathology.

Postsurgical pain, scar tissue and a protective posture may lead to shortening of tissues in the pectoral region which would result in a protracted depressed position of the scapula[42]. Scar tissue, specifically, may impair the normal gliding between skin layers, fascia and muscles that are necessary for normal movement. Further, pain or fear of using the affected arm may lead to limited movement, muscular atrophy and adaptive shortening of the shoulder joint capsule and surrounding muscles. Finally, fibrosis from radiation therapy may pull the shoulder girdle forward, exacerbating the malalignment, decreasing the tissue flexibility, and restricting motion[43]. Together these changes may lead to altered shoulder girdle motion and painful limitations in upper-body functioning.

In addition, women undergoing treatment for breast cancer may already be at risk for developing shoulder pathology. Degeneration of the rotator cuff tendons is a part of normal ageing, and the prevalence of asymptomatic partial or full tears increase significantly after the age of 50 years[44]. Among women diagnosed with breast cancer in Canada, 81% are 50 years or older [45], and likely have underlying degenerative rotator cuff changes. Treatment for breast cancer may then trigger the development of symptomatic rotator cuff disease or other shoulder pathologies. Taken together, these biomechanical changes and painful movements lead to limitation in the ability to perform activities of daily living, return to work, participate in recreational activities and are associated with decreased health-related quality of life[6].

1.3.1.1 Definitions and Prevalence of Upper-Body Issues

Interpretation of the following prevalence rates is complicated by the fact that they are reported for various time points along the survivorship continuum and for a variety of treatment combinations. Further, different definitions are employed for the impairments which directly impacts the prevalence rates. Still, the point is made that BCSs experience significant post-treatment upper-body issues. These issues may also persist much longer than reported in the studies due to limited follow-up.

1.3.1.1.1 Shoulder Range of Motion

Definitions of impaired ROM are based on: 1) self-report; 2) therapist evaluation of "decreased mobility"; or 3) therapist-measured decreases of ≥ 10˚or 10% compared to the unaffected arm or pre-surgery measures using a goniometer[46]. The prevalence rates of impaired shoulder ROM is reported in up to 67% among women who have undergone surgery and radiation therapy[47–49]. One systematic review of 32 studies reported a reduction in ROM after ALND surgery in shoulder abduction and flexion ranging from 132˚ to 175˚, which was reported in 1% to 67% of the patients[48]. Regarding SLNB, a second systematic review of 32 studies (not the same 32 studies) described a reduction in ROM among 6% to 31% of patients at 12 months post-surgery, and ≤ 9% at 24 months[50]. A third systematic review of 22 studies compared ALND to SLNB and reported prevalence rates of 9% to 56% (ALND) vs. 3% to 24% (SLNB)[46]. Similarly, the prevalence of impaired ROM is affected by radiation therapy with prevalence rates of 34% to 56% after receiving radiation therapy compared to 4% to 20% in patients without radiation therapy[46]. Loss in abduction is generally the greatest shoulder ROM impacted (7˚ to

33˚), followed by flexion (3˚ to 17˚), external rotation (1˚ to 11˚) and internal rotation (1˚ to 4˚)[51–54].

1.3.1.1.2 Upper-body Muscle Strength

Muscle strength is measured by physical therapists (PTs) using manual muscle testing or handheld dynamometry and generally includes shoulder abductor, flexor, and rotator muscles and hand grip strength. No cut off points are employed in the definition of impaired muscle strength, but is evaluated as the difference from pre-surgery or between affected and unaffected arms[48,55]. The prevalence rates of impaired muscular strength range from 0% to 60% after ALND and 0% to 35% after SLNB[48,49,55]. One systematic review of 22 studies reported average decreases of 12 to 15 Newton meter (Nm) in shoulder abduction and 12 to 41 Nm in hand grip strength[46].

1.3.1.1.3 Upper-body Pain and Tightness

Pain and tightness are patient reported as a dichotomous variable (yes/no), or using a visual analogue scale with ≥ 3 indicating pain/tightness[48]. Prevalence of upper-body pain range from 9% to 68% while tightness range from 15% to 72%[48,49]. Unfortunately, the type of treatment for these prevalence rates is not reported.

1.3.1.1.4 Upper-body function

Limitations in upper-body function is patient-reported and definitions used include dichotomous yes/no to "whether or not the patient have had to give up any activities because of the treatment"[56], or a score of ≥ 21.5 on Kwan's arm problem scale[57]. To date, at least three

systematic reviews[46,50,58] have described limitations in upper-body function. However, one major limitation when summarizing the prevalence rates of impaired upper-body function is that only few studies report prevalence. This is likely due to an absence of cut off points/thresholds for most patient-reported instruments to identify patients with or without limitations in upper-body function. Two cross-sectional studies have reported prevalence rates of impaired function among 31% of 255 patients at an average 4.1 years after surgery[57] and 34% of 940 patients at a range of 25 to 34 months post-surgery[56]. One cohort study of 191 patients found prevalence rates of 39% to 44% after ALND, 18% to 19% after SLNB, and 12% to 19% after lumpectomy surgery[59].

1.3.2 Mechanistic Causes of Breast Cancer-related Lymphedema

Breast cancer-related lymphedema (BCRL) is swelling of the arm, breast, or chest and a chronic effect of breast cancer treatment. BCRL is the result of obstruction or disruption of the lymphatic system associated with the treatment (e.g. removal of lymph nodes and/or radiotherapy) and influenced by patient factors (e.g. higher BMI)[60]. The exact pathophysiology and time it takes for the progression is not fully understood, but it is clear that progression is driven by hydrostatic and osmotic changes in the lymphatic system and is accelerated by inflammation and infection[61,62]. BCRL develops in two phases, an early reversible phase with no fibrosis, and a later chronic phase with irreversible intradermal fibrosis[63]. This pathophysiology provides a window of opportunity to prevent the development of chronic BCRL by intervening in the early reversible phase. Chronic BCRL leads to irreversible structural changes, such as impaired elasticity of the skin, interstitial fibrosis or atrophy of the smooth muscle within the lymphatic walls resulting in impaired ability for the vessels to create lymph fluid propulsion[64,65]. BCRL due to radiation therapy is thought to develop by increasing the fibrosis and infiltration of

lymphatic structures. Recent data suggest that 89% of BCRL cases develop within the first three years after surgery for breast cancer[66–69], but it may also manifest many years post-treatment[70,71]. Common initial symptoms for BCRL include swelling, discomfort, pain, heaviness, tightness, impaired shoulder mobility, altered sensation in the affected arm with hypersensitivity or lack of sensitivity and a decrease of general daily function[71–73]. Further, the increase in weight of the arm results in a greater load being applied to the rotator cuff muscles and tendons, which may contribute to tendon overload and increased risk of developing shoulder pathologies, such as rotator cuff disease[74].

1.3.2.1 Classification and Prevalence

BCRL is classified in 4 stages[75–77]: Stage 0 is *subclinical* lymphedema with initial symptoms without visible swelling and has the potential for symptom reduction quickly and with minimal intervention; Stage 1 is *mild* BCRL with swelling of 10% or 200ml compared to unaffected arm while treatment can reverse the swelling; Stage 2 is *moderate* BCRL with some irreversible tissue changes with persistent swelling that is more difficult to manage; and Stage 3 is *severe* BCRL with chronic tissue and skin damage with limited ability to manage[75–77].

The prevalence of BCRL differs by surgical approach. Systematic reviews and meta-analysis demonstrate a pooled incidence of BCRL of 16.6% which ranges from 11.8% to 53.5%[78] or 0% to 15.8%[79] for ALND and SLNB, respectively. A recently published prospective cohort of 1,073 women with early stage breast cancer demonstrated the incidence of post-surgery arm swelling as 34.5% with 23.3% progressing to persistent BCRL at 5.1 years post-surgery[80]. The considerable variation in incidence rates are due to methodologic differences in definition, methods used for measuring, variations in surgical or radiation treatments, and the length of

follow-up between studies. The lack of clear streamlined assessments, diagnosis, and registry of incident cases result in lack of knowledge into the prevalence of BCRL in Canada[81]. However, over the past 10 years, 158,430 Canadian women have been diagnosed with breast cancer and are still alive today[45]. Of those, an estimated 6% to 20% will develop BCRL based on treatment and personal factors[78], which corresponds to 9,505 to 31,686 women living with BCRL in Canada.

1.3.2.2 Prevention and Management

Despite great effort, there remain no modality to prevent the onset of BCRL. A 2015 Cochrane review of four randomized controlled trials (RCTs) testing the effectiveness of manual lymph drainage (MLD), a gentle massage technique, for preventing BCRL were unable to draw conclusions regarding this modality[82]. However, two robust 2018 RCTs with BCRL as their primary outcome demonstrated that MLD does not have a preventive effect on BCRL in the short or long term[83,84].

Different modes of exercise (yoga, Nordic walking, resistance training) can aid in reducing the BCRL volume[85] and provide well-documented benefits for BCSs with pain, mobility and strength limitations[86,87]. However, exercise does not seem to prevent the onset of BCRL[88].

Recent work has suggested the prophylactic use of compression garments to prevent the onset of BCRL. The RCT by Ochalek and colleagues compared an intervention (wear of a light compression garment 10 hours/day and a physical activity program (n = 23)) to control (physical activity program only (n = 22)) on the development of BCRL[89,90]. Although, the incidence of BCRL was lower in the intervention group (3 of 20) than in the control group (6 of 21), the lack of statistical comparison hampers the interpretability. Edema volume was decreased in the intervention group at 12 months[89] but not at 24 months follow-up[90]. While the results are

promising, the use of prophylactic daily wear of compression garment for all at-risk BCSs may not be ideal as only a subset of BCSs will need this intervention which risks to overtreat and pathologize survivors who will not develop BCRL.

Complex decongestive therapy (CDT) is currently viewed as the best management for BCRL[85,91,92]. The therapy involves four components: 1) skin care to avoid infection; 2) compression garment or multilayered bandaging to avoid filtration of lymph fluid into the tissue; 3) rehabilitation exercises to maintain/regain shoulder mobility and muscle strength, and 4) MLD. Treatment for BCRL is generally initiated when an increase of 5% to 10% in arm volume is identified, while more intensive treatment is initiated with > 10% increase compared to the unaffected arm or pre-surgery measures[93].

1.4 Measurement of Breast Cancer-related Upper-body Issues

Reliable and valid outcome measurement is a cornerstone in rehabilitation intervention care and research. The most commonly used outcome measures in physical rehabilitation of breast cancer-related upper-body issues, their classification within International Classification of Functioning (ICF), their psychometric properties and applicability to cancer rehabilitation and rehabilitation in general are listed in Table 1.1. The special tests and measures used by the PTs to measure limitations in body structure and function in BCSs are often not unique to the assessment of this population. In upper-body rehabilitation, these outcomes are focused on the sensory, movement and immunologic systems and are mostly therapist-administered. When selecting appropriate outcome measures, first step is to identify the goal of the intervention and secondly consider the psychometric properties of the measures. Most rehabilitation interventions are directly aimed at improving outcomes of body function and structure, with the (indirect) goal

to improve outcomes in activity and participation. Outcome measures across the functional domains should therefore be included in rehabilitation research. Further, outcomes should be validated in the (breast) cancer population. Lastly, interpretation of the efficacy of a research intervention or effectiveness of a clinical program requires knowledge about the minimal detectable (and clinical) difference of the outcome measure. In clinical practice, the minimal detectable change (MDC) is one of the most important values to consider when using objective outcome measurements[94]. The MDC is a function of the measurement error and is the minimum amount of change in a patient's score that ensures the change is not the result of measurement error. The MDC is reported for most outcome measures listed in table 1.1 while rarely reported specifically for a breast cancer population.

Numerous patient-reported instruments and some therapist-administered instruments are used to measure activity limitations and participation restrictions. Most of these instruments have been developed for other disease populations and their psychometric properties have not been established among BCSs.

Environmental and contextual factors may explain adherence and effect of rehabilitation interventions but are not included in the outcome measures listed in Table 1.1. However, identifying barriers/facilitators in the environment are important to tailor the intervention mode to gain better adherence and outcomes. In rehabilitation research, personal and health/disease-related factors are systematically collected, along with environmental factors to some degree, and are utilized to investigate their role as covariates, predictors, confounders or mediators for the outcomes of interest. For example, environmental (living alone), and disease-related factors (surgery and axillary dissection type) have been demonstrated to predict upper-body issues at 12 months after breast cancer surgery[95], while personal (income, personality, coping strategies),

environmental (social support) and disease-related factors (cancer stage) can predict psychological adjustment in BCSs[96].

Table 1. 1 Outcome measures in breast cancer rehabilitation

Outcome	Measurement tool	Characteristics	Psychometric properties	
ICF CONSTRUCT: BODY STRUCTURE & FUNCTIONING				
Sensory functions and pain				
Pain	Visual analogue scale*^	Unidimensional measure of pain intensity, scores 0 (no pain) to 10 (worst pain)[97,98]	**MCID** 3[99]	
	Numeric rating scale*^	Unidimensional measure of pain intensity, scores 0 (no pain) to 10 (worst pain)[100]	**MDC** 4[101]§	
Neuro-musculoskeletal and movement-related functions and structures				
Joint mobility	Goniometry*^	Mechanical measure	**Intra-rater SEM**[102] Flex: 2˚ Abd: 2˚ Ext. rot: 3˚ Int. rot: 2˚ **MDC** Flex: 4°[103] Abd: 6°[103] Ext. rot: 7°[94] Int. rot: 4-7°[94] Ext. /Int. rot 4.4-8.0°[94]	**Inter-rater SEM**[103] Flex: 6˚ Abd: 11˚ Ext. rot: 7˚ Int. rot: 11˚ **MDC**[103] Flex: 15˚ Abd: 26˚ Ext. rot: 18˚ Int. rot: 27˚
	Inclinometer*^	Digital measure that use constant gravity as a reference point to assess joint mobility	**Intra-rater SEM**[102] Flex: 2˚ Abd: 2˚ Ext. rot: 2˚ Int. rot: 2˚ **MDC**[94,104] Ext. /Int. rot 4.0-6.4˚	**Inter-rater MDC**[94] Ext. /Int. rot 2.8-5.5˚
	Goniometric mobile apps*^	Smartphone-based goniometer applications	**Intra-rater SEM**[103] Flex: 2˚ Abd: 4-6˚ Ext. rot: 3˚ Int. rot: 2-3˚ **MDC**[103] Flex: 2-12˚	**Inter-rater SEM**[103] Flex: 10˚ Abd: 14˚ Ext. rot: 9˚ Int. rot: 10˚ **MDC**[103] Flex: 23˚

			Abd: 3˚ Ext. rot: 2-3˚ Int. rot: 3˚	Abd: 32˚ Ext. rot: 19˚ Int. rot: 25˚
	Sit-and-reach*^	Performance test of general flexibility	NR	
Muscle strength	Manual muscle testing (MMT)*^	Standardized performance test that measures the patient's ability to resist against therapist-applied force	NA	
	Handheld dynamometer*^	Mechanical measure of force with normative values of upper-body strength for healthy women[105,106]	**Intra-rater MDC**[94] Ext. rot: 7.8N Int. rot: 22.1N	**Inter-rater MDC**[94] Int. rot: 26.6N
	Hand grip dynamometer *^	Mechanical measure of force	**MCID**: 6.5 kg[107]	
Movement functions	Lymphedema-related Fibrosis Scale*	This three-level scale provides standardized language to describe fibrosis of tissue due to scarring or radiation therapy[108]	NA	
Functions of the immunologic system - Lymphatic system				
Limb volume	Water displacement*	Direct, quantitative measure of limb volume		**Inter-rater SEM**: 66.5 to 81.7ml[109] **MDC**: 154.3 to 189.5ml[109], 3.6% (±2.7%)[110]€
	Perometry*	Direct, quantitative measure of limb volume using computer analysis of a scanned image of the limp to calculate circumference and volume	**SEM**: 2.3%[111], 6.7%[112] **MDC**: 5.6% (±4.2%)[110]€	
	Circumference and a truncated cone formula*	Indirect, quantitative measure of limb volume		**Inter-rater SEM**: 64-71mm[109]ǂ **MDC**: 149-165mL[109]ǂ, 6.6% (±2.6%)[110]€
	Bioimpedance electrical analysis (BIS)*	BIS is a technology that measures the resistance to a very small electrical signal applied to the arm. It produces a lymphedema-index (L-Dex) score based on the amount of extra cellular fluid in the arm.	**SEM**: 0.05[111] **MDC**: 29.2ohm[111]√	
Lymphatic impairment	Cording Scale*	This three-level scale provides standardized language to describe cording due to impairments in the lymphatic system[108]	NA	
ICF CONSTRUCTS: ACTIVITY & PARTICIPATION				
Upper-body function	Kwan's arm problem scale (KAPS)	Consists of two subscales; the Problem subscale with 8 items and scores from 8 to 40 points, the ADL subscale with 5 items and scores 5	**MCID**: 21.5[119]√	

	to 25 points[72]. Higher score indicate more disability. Developed to measure breast cancer-related upper-body issues.	
Disabilities of Arm and Shoulder and Hand (DASH)*^	30-item questionnaire. Scores from 0 to 100 with higher scores indicating more disability.	**MDC**: 6.3[120]§, 12.2[121]§ **MCID**: 10 (95% CI 5-15)[122]§, 10.2[121]§, 10.8[123]§, 12.4[120]§ 15[121]§ **Cut-off scores**: NE
QuickDASH*^	11-item questionnaire. Scores 0 to 100 with higher scores indicating more disability.	**MDC**: 11.2[124]§, 17.1[120]§ **MCID**: 8[124]§, 13.4[120]§ 14 (95% CI 9-20)[122]§ 15.9[123]§ **Cut-off scores**: NE
Constant Shoulder Score/Constant-Murley score*^	Combined clinician and patient-administered scale with 8 items[125]. Scores 0 to 100 with higher scores indicating higher functional status.	**MDC**: 17 to 23[126]§. **MCID**: NE **Cut-off scores**: NE
Upper Extremity Functional Index (UEFI)*^	20-item questionnaire. Scores 0 to 80 with higher scores indicating higher functional status.	**MDC**: 9[127] **MCID**: 8.5[128] **Cut-off scores**: NE
Shoulder Pain and Disability Index (SPADI)*^	13-item questionnaire. Scores 0 to 130 with higher scores indicating more disability[129].	**MDC**: 18.1[130]§ **MCID**: 3.2[130]§ **Cut-off scores**: NE
Functional Index Score*^	10-item questionnaire. Scores 0 to 40 with higher scores indicating more disability.	NR
The Modified-University of California at Los Angeles Shoulder Rating Scale (UCLA Scale)*^	A clinician-administered rating scale with domains of pain, active shoulder ROM, manual muscle testing, ADL function and patient satisfaction[132]. Scores 0 to 36 with higher scores indicating "better patient outcome".	**MCD**: NA **MCID**: NA **Cut-off points**: Scores are categorized into poor (20), fair (21-27), good (28-33) excellent (34-36)[133]
American Shoulder and Elbow Score (ASES)*^	16-item questionnaire. Scores 0 to 100 with higher scores indicating more disability.	**MDC**: 9.7[134]§ **Cut-off scores**: NE
Upper Limb Disability Questionnaire*^	27-item questionnaire. Produces four categories of disability.	NR[128,129]

Legend: *: Applicable to cancer rehabilitation. ^: Applicable to general rehabilitation. ROM: range of motion. SEM: standard error of measurement. MDC: minimal detectable change. MCID: minimal clinical important difference. NR: not reported. NA: not applicable. NE: not established. §: established among people with upper body issues, not in a breast cancer population. √: established in a breast cancer population. ⏚: depends on circumference measurement protocol. €: data from meta-analysis

1.5 Physical Rehabilitation for Breast Cancer Survivors

Cancer rehabilitation constitutes an umbrella concept in cancer care[137] and involves helping a person with cancer to help himself or herself to obtain maximal physical, social, psychological, and vocational functioning within the limits imposed by disease and its treatment[138]. Physical rehabilitation for breast cancer-related upper-body issues is a distinct scientific field and one element of cancer rehabilitation research. Treatment goals of upper-body rehabilitation include returning to pre-surgery activities and participation using physical therapy modalities that target upper-body structure and function including passive mobilizations of the shoulder joint, manual stretching, myofascial therapy and active rehabilitation exercises.

Table 1.2 outlines the RCTs of rehabilitation for BCSs at high risk for upper-body issues. Most commonly, BCSs with ALND[139–143] in combination with mastectomy surgery[114–116,144–148], or BCSs who have ≤ 100˚ shoulder flexion/abduction ROM[133] on the first post-operative day have been eligible to participate in these studies. Generally, the studies demonstrate that physical therapy modalities are effective in regaining shoulder ROM and improve the ability to undertake activities of daily living (ADL). A Cochrane review of 24 RCTs with 2,132 participants summarized the benefits of upper-body rehabilitation; compared to control, rehabilitation improves shoulder ROM and ADL, and does not influence the development of BCRL. When comparing rehabilitation initiated early (generally 1st post-surgery day) compared to delayed (generally one week post-surgery) no clinically important differences were found for shoulder ROM and ADL, but early rehabilitation was reported to increase the prevalence of post-surgery complications[86]. Since then, improved surgical instruments and softer drains have been

developed which may lower the development of post-surgical complications[11] and enable safe early start of rehabilitation.

Table 1. 2 Randomized controlled trials of rehabilitation for women at risk of upper-body issues

Author (year)	Population	Sample size	Intervention	Outcome measures	Follow-up	Results
Rehabilitation compared to education/usual care						
Wingate[116] (1989)	Women w ALND and MAST	Rehab n = 61 Control n = 54	Supervised and home-based rehab Duration: 2/day for 30 min until discharge. Home-program for 8ws Timing: immediately post-op Control: no therapy	ROM: goniometer BCRL: CIR ADL: home-made Q	1-3M	ROM: ↑ BCRL: ND ADL: ↑
Box[139] (2002)	Women w ALND	Rehab n = 33 Control n = 32	Supervised rehab Duration: NR Timing: immediately post-op Control: information	ROM: goniometer ADL: home-made Q	12M 24M	12M: ROM: ND ADL: ND 24M: ROM: ↑ ADL: ND
Cho[149] (2006)	Women w MAST	Rehab n = 25 Control n = 25	Supervised and home-based rehab, psychology-based education, peer support group Duration: 3/w for 10ws Timing: within 2yrs post-treatment Control: same intervention after study completion.	ROM: goniometer QoL: Korean Q Psychosocial adjustment	Post-intervention	ROM: ↑ QoL: ↑ Psychosocial adjustment: ↑
Beursken[145] (2007)	Women w ALND	Rehab n = 15 Control n = 15	Supervised rehab Duration: 3M Timing: 2ws post-op Control: information	ROM: inclinometer Strength: HHD Pain: VAS BCRL: WD ADL: DASH	3M 6M	3M: Pain: ↓ 6M: Pain: ND Both time points: ROM: ↑ ADL: ↑ BCRL: ND Strength: ND
Kilgour[150] (2008)	Women w ALND and MAST	Rehab n = 16 Control n = 11	Home-based rehab w video Duration:2-3/day for 11 days Timing: from 3rd to 14th post-op day Control: usual care	ROM: goniometer Strength: MMT and HHD	Post-intervention	ROM: ↑ Strength: ND BCRL: ND Pain: ND

Author (year)	Population	Sample size	Intervention	Outcome measures	Follow-up	Results
				BCRL: CIR Pain: CR-10		
Supervised rehabilitation initiated early compared to delayed						
Van der Horst[140] (1985)	Women w ALND	Early n = 31 Delayed n = 28	Early: 1st post-op day Delayed: 1w post-op Duration: 14 days	ROM: NR Wound drainage	6M	ROM: ND (compared to pre-surgery) Wound drainage: ND
Schultz[146] (1997)	Women w ALND and MAST	Early n = 89 Delayed n = 74	Early: 1st post-op day Delayed: 1w post-op Duration: NR	ROM: NR Seroma	4-6M	ROM: ND Seroma: ↑ (38 vs 22%) in early group
Jansen[141] (1990)	Women w ALND	Early n = 78 Delayed n = 66	Early: 1st post-op day Delayed: 1w post-op Duration: until ROM regained	ROM: NR BCRL: NR Wound drainage	6M	ROM: ND BCRL: ND Wound drainage: ND
Abe[144] (1998)	Women w ALND	Early n = 58 Delayed n = 58	Early: 1st post-op day Delayed: 1w post-op Duration: NR	ROM: NR Seroma Wound drainage	1M	ROM: ND Seroma: ↑ (46 vs 27%) in early group Wound drainage: ↑ in early group
Chen[148] (1999)	Women w ALND and MAST	Early n = 116 Delayed n = 115 Late n = 113	Early: 3rd post-op day Delayed: 6th post-op day Late: when drains were removed Supervised/home: NR Duration: NR	ROM: NR Wound drainage	2M 6M	Both time points: ROM: ND Early/delayed vs late group: ↑wound drainage
Bendz[147] (2002)	Women w ALND	Early n = 101 Delayed n = 104	Early: 1st post-op day Delayed: 2ws post-op Duration: NR	ROM: goniometer Pain: VAS Strength: vigorimeter BCRL: WD	6M 2 yrs	Both time points: ROM: ↑ in early group Strength: ND BCRL: ND
Lauridsen[143] (2005)	Women w ALND	Early n = 72 Delayed n = 67	Early: 6-8 ws post-op Delayed: 26ws post-op Duration: until ROM regained	ADL: Constant Shoulder Score	6 ws 12 ws 26 ws	6 ws: ↑ADL 12 ws: ↑ADL 26 ws: ↑ADL

Author (year)	Population	Sample size	Intervention	Outcome measures	Follow-up	Results
					56 ws	56 ws: ND
Todd[142] (2008)	Women w ALND	Early n = 58 Delayed n = 58	Early: 1st post-op day Delayed: 1w post-op Duration: NR	ROM: goniometer Strength: HHD BCRL: WD QoL: FACT-B+4 Wound drainage	12M	ROM: ND (-11˚ vs -3˚ p=0.06) Strength: ND BCRL: ↑ (28 vs 10%) QoL: ND Wound drainage: ↑
Supervised compared to non-supervised rehabilitation						
De Rezende[115] (2006)	Women w ALND	S n = 30 Non-S n = 30	Supervised rehab Duration: 3/w for 42 days Timing: immediately post-op Non-S: same but non-supervised	ROM: goniometer BCRL: CIR	Post-intervention	ROM: ↑ BCRL: ND
Cinar[114] (2008)	Women w ALND and MAST	S n = 27 Non-S n = 30	Supervised rehab Duration: 15 sessions/8 ws Timing: immediately post-op Non-S: home-program	ROM: goniometer BCRL: CIR ADL: FIS	3M 6M	Both time-points: ROM: ↑ BCRL: ND ADL: ↑
Pace do Amaral[133] (2012)	Women w ALND and ≤100˚ in flex/abd at 1st post-op day	Intervention n = 65 Comparison n = 66	Intervention: Group-based rehab and manual therapy Duration: 45min 3/w for 4ws (rehab); 20min 2/w for 4ws (manual therapy) Timing: immediately post-op Comparison: group-based rehab w/o manual therapy	ROM: goniometer ADL: UCLA	6M 12M 18M	All time-points: ROM: ND ADL: ND
Physical rehabilitation with/without manual treatment						
Cho[151] (2016)	Women w pain (NRS>3) and cording	Rehab n = 20 Rehab + MLD n = 21	Supervised rehab Duration: 3/w for 4 wks Supervised rehab + MLD Duration: 5/w for 4 wks	ROM: inclinometer Pain: NRS Strength: HHD BCRL: CIR ADL: DASH QoL: EORTC	Post-intervention	ROM: ND Pain: ↓ Strength: ND BCRL: ↓ ADL: ND QoL: ND

Legend: Abd: abduction. ADL: activities of daily living. ALND: axillary lymph node dissection. BCRL: breast cancer-related lymphedema. BCS: breast conserving surgery. CR-10: Borg's Category Scale for Rating of Perceived Pain (0-10). EORTC: European Organisation of Research and Treatment for Cancer. FACT-B+4: Functional Assessment of Cancer Therapy- Breast. FIS: functional index score. Flex: flexion. HHD: handheld dynamometer. M: months.

Author (year)	Population	Sample size	Intervention	Outcome measures	Follow-up	Results

MAST: mastectomy. MLD: manual lymph drainage. ND: no difference between groups. NR: not reported. NRS: numeric pain rating scale (0-10). Non-S: non-supervised. Post-op: post-operative. Q: questionnaire. Rehab: rehabilitation. ROM: range of motion. S: supervised. SLNB: sentinel lymph node biopsy. UCLA: University of California at Los Angeles Shoulder Rating Scale. w(s): week(s) WD: water displacement. yrs: years.

1.5.1 Canadian Guidelines and Current Clinical Practice

National and international cancer guidelines recommend that rehabilitation is offered from point of diagnosis to mitigate functional disability[152]. The Canadian clinical practice guideline published by Harries et al. in 2001 recommends that all BCSs perform upper-body rehabilitation after surgery for breast cancer[153]. The rehabilitation should be initiated one week post-surgery and continued over an extended period of time while soft tissue heals and remodels. Further, survivors should learn about BCRL risk-minimizing behaviours[154] including skin care, specifically keep skin clean, avoid puncture of skin and observe signs of infection, exercise, avoid extreme temperatures, and to wear compression garments when prescribed[155].

Today, a limited number of facilities (public and private) deliver specialized physical rehabilitation for people with cancer or specific to BSCs. A cross-Canadian survey published in 2013 identified only 20 sites (of 116 surveyed) that delivered physical rehabilitation for cancer survivors[156]. Most sites (75%) were in cities with > 500,000 citizens, and no sites were located in cities with < 50,000 citizens. Four sites reported that services provided met the rehabilitation needs of their patients, while the remaining sites reported barriers around access to equipment, trained therapists, and space. Further, with the financial structure of Canadian healthcare, only publicly delivered rehabilitation is covered under provincial health insurance plans, while the tertiary care delivered by licensed PTs in private practice requires out-of-pocket payment from the patient (in the case of no extended health insurance provided through own or spouse's employer). This creates disparity in access to oncology rehabilitation for individuals who live in rural settings, or individuals without employer-provided health insurance, who may therefore have little opportunity to follow the recommendations for upper-body rehabilitation. Further, it is currently unknown to what extent BCSs who have extended health insurance seek rehabilitation

services delivered in the tertiary sector. A key question is therefore identifying the ideal structure for delivering oncology rehabilitation in general and specifically for BSCs in Canada.

1.5.2 Recommendations for Canadian Cancer Rehabilitation Care and Research

A Cancer Journey Survivorship Expert Panel comprised of researchers and clinicians published a Canadian guideline in 2011 on organization and care delivery structure for cancer survivorship services[157]. The guideline was based on a systematic review of fourteen practice guidelines, eight systematic reviews and sixty-three randomized controlled trials and was intended to inform Canadian health authorities, policy decision-makers, healthcare practitioners, survivors and their caregivers about the optimal structure for survivorship services. It identified a need for the development of specific survivorship programs that include a range of rehabilitation services to meet the diverse needs of cancer survivors. Such programs could be established in collaboration with local communities and supported by technology to provide rapid access[157]. In line with this, a group of experts, survivors and clinicians from across Canada identified the main research priority: "to develop and test personalized rehabilitation interventions and brief (outcome) measures to identify the presence and severity of disabling sequelae." [158 p. 68]. Further, a need for research into ways to overcome challenging contexts such as rural and remote communities was articulated, along with development and evaluation of a referral process to ensure that individuals receive appropriate rehabilitation services at the right time[158].

These recommendations for cancer rehabilitation in Canada are to move the field of research from testing fixed, standardized rehabilitation programs delivered at certain locations at certain times along the treatment trajectory (such as the studies listed in Table 1.2) towards

individualized rehabilitation programs anchored within the communities delivered in a mode that is accessible, and evaluated using brief patient-administered outcome measures.

1.5.3 Models of Rehabilitation Delivery

Several models of delivery of rehabilitation for cancer survivors have been described including the disease-specific model[159], the comprehensive cancer care model[160–162], the community-based shared care model[159,160,163], the chronic care model[164,165] and the prospective surveillance model[166]. Following paragraphs will outline the prospective surveillance model and the research utilizing this model for management of breast cancer-related upper-body issues. Following this, then the self-management approach and health behavioural theories will be outlined and how they may be utilized when designing and testing surveillance and rehabilitation programs.

1.5.3.1 Prospective Surveillance and Targeted Rehabilitation

Prospective surveillance is one approach for delivery of rehabilitation developed by experts in the field assembled by the American Cancer Society[166]. This approach utilizes therapist-administered assessments at pre-surgery, and scheduled ongoing post-surgery assessments at set intervals to detect upper-body issues and only if detected, to provide targeted delivery of treatment[166,167]. The rehabilitation is individualized in terms of initiation, frequency, content and duration. Table 1.3 outlines the studies to date of prospective surveillance and rehabilitation for women with upper-body issues. A number of cohort[168–172] and case-control[173–176] studies and three small RCTs ($n < 60$ per group)[177–179] have utilized a therapist-administered surveillance program and together suggest the potential ability of this approach for preventing chronic BCRL.

Further, a handful of studies have utilized this approach to identify and treat impaired shoulder ROM, muscle strength, upper-body function and pain[118,136,179–181].

As the literature has predominantly been observational, it lacks the ability to demonstrate causality and control for confounding variables. Only one RCT has reported significant results with a reduced incidence of BCRL (7% vs 25%, $p = 0.01$) using a surveillance protocol ($n = 59$) compared to control ($n = 57$)[178]. Second, the majority of research has been conducted in the United States where healthcare insurance (or personal financial resources) is necessary to access hospital-based surveillance programs. Since the sociodemographic characteristics (i.e., education or income) of the samples are not reported, it is unclear if only resourceful participants have been included. Nevertheless, while these studies provide support for this approach more work is needed using well-powered controlled trials to validate and verify the effect.

Despite the limited evidence from RCTs to date, there is a growing consensus among clinical researchers (PTs and physicians from Europe and North America) that prospective surveillance is the ideal approach for management of BCRL[118,182,183]. As a result, several hospitals[170–172] in the United States have implemented the model and report low prevalence rates of chronic BCRL (3%[171] to 6%[172]). However, since these services are provided at a cost, such programs risk increasing the inequity of health among American survivors. Furthermore, the main barriers for implementing this approach in publicly-funded healthcare are access to trained professionals, access to sophisticated measurement tools to identify BCRL, and the associated cost of long-term surveillance for a large at-risk population. These barriers highlight the need to consider other delivery strategies, such as a self-management approach, to increase the reach and equity of access to surveillance programs.

Table 1. 3 Prospective surveillance and rehabilitation for women with upper-body issues

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
Breast cancer-related lymphedema						
Box[177] (2002)	RCT	Women w early stage breast cancer and ALND Int n = 32 Control n = 33	**Measurement protocol:** pre-surgery and post-surgery at day 5 and 1, 3, 6, 12, 24M **Women w BCRL**: "self-management program" and intensive complex therapy program as needed	BIS and CIR **Def. of BCRL**: ≥5cm or L-DEX ≥10% from pre-surgery	24M	↓ BCRL 11 vs 30%, p = 0.08
Stout[173] (2008)	Pro. case-control	Women w unilateral early stage breast cancer. 81-83% had ALND Cases w subclinical BCRL n = 43 Control w/t BCRL n = 43	**Measurement protocol:** pre-surgery and post-surgery at 1, 3, 6, 9, 12, 18 months **Everybody**: rehabilitation program and education material about BCRL prevention. **Women w BCRL**: compression	Perometer **Def. of subclinical BCRL**: ≥3% compared to pre-surgery	Average 4.8M from identification of BCRL	↓ BCRL volume -4.8% ± 8.8
Torres Lacomba[178] (2010)	RCT	Women w unilateral breast cancer and ALND Int n = 59 Control n = 57	**Measurement protocol:** post-surgery at 1, 3, 6, 12 M **Control:** information **Women w BCRL:** Decongestive therapy	CIR **Def. of BCRL**: >2cm at two points compared to unaffected arm	12M	↓ BCRL 7 vs 25%

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
Johansson[174] (2010)	Retro. case-control	Women w unilateral breast cancer, ALND and radiation therapy Cases n = 98 Control n = 40	**Measurement protocol:** Bi-yearly for up to 10 years **Women w BCRL:** Compression and information about self-management. Women w ≥5% since last visit or ≥20% dif. btw. arms received decongestive therapy	WD **Def. of BCRL**: ≥5% and skin thickness compared to unaffected arm	Cases: 43±33M Control: 73±30M	Cases: Average time from surgery to BCRL: 11.5±12.8M. No significant increase in arm size relative to unaffected arm from diagnosis to follow-up (9±7% increase)
Soran[168] (2014)	Pro. Cohort	Women w unilateral, any stage breast cancer. Proportion of ALND not reported n = 180 BIS n = 136 Control n = 44	**Measurement protocol:** pre-surgery and post-surgery at 3-6M, and 1, 2, 3, 4, 5yrs BIS were assessed w CIR and BIS Control were assessed w CIR and BIS **Women w BCRL:** "early intervention"	CIR and BIS **Def. of BCRL**: ≥2cm at one point compared to unaffected arm **Subclinical BCRL**: L-DEX outside normal rage of ±10	20M	↓ BCRL in BIS group BIS group: 33% developed subclinical BCRL. 4.4% progressed to clinical BCRL Clinical BCRL 36.4% (control) vs 2.8% (BIS)
Erdogan[169] (2015)	Retro. cohort	Women w early stage, unilateral breast cancer. 76% had ALND n = 37	**Measurement protocol:** pre-surgery and post-surgery at 3, 6, 9, 12M **Women w BCRL:** Decongestive therapy	BIS and CIR **Def. of BCRL**: L-DEX outside normal rage of ±10	12M	In total, n=8 (21.6%) developed BCRL Stage 0: n=3 Stage 1: n=1 Stage 2: n=4
Laidley[184] (2016)	Retro. cohort	Women w any stage breast cancer. 36% had ALDN	**Measurement protocol:** pre-surgery and post-surgery every 3M until 24M	BIS **Def of BCRL:** >10 L-DEX from pre-surgery	21.7M (3.7 to 54)	Incidence of BCRL: n=9, 4.3% for SLNB n=31 26.7% for ALND Of the n=31 participants

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
		n = 326	**Women w BCRL:** compression, massage and/or physical therapy determined by physician			who underwent treatment, 61.4% of cases were resolved. Mean time to onset 5.6 to 7.5 M post-surgery. n=30 participants had symptoms of swelling and not L-DEX >10 and wore compression. No cases progressed to BCRL.
Akita[185] (2016)	Pro. cohort	Women w any stage breast cancer and any treatment. 71 (38%) had ALND n = 189	**Measurement protocol:** Pre-surgery and post-surgery at 1, 3, 6, 9, 12M **Women w BCRL:** compression garment + advice reg. skin care, exercise and elevation	CIR and lymphatic images **Def. of BCRL:** >10% volume increase from pre-surgery Def. of lymphatic disorder: "stardust", "diffuse" or "no flow" using the imaging device.	20.1±3.5M	35 (18%) developed lymphatic disorder. Of these, 14 had BCRL. 11 cases were resolved. 24 cases continued daily compression. In some cases who resolved, development of collateral lymph routes was observed (supplemental video).
Yang[175] (2016)	Pro. cohort w historical control group	Women w unilateral early stage breast cancer and ALND Surveillance n = 390 Control n = 317	**Measurement protocol:** Every 3M for first year post-surgery, then biyearly. **Women w BCRL:** Compression and education on MLD for 4 wks. BCRL stage 0 and 1 commenced progressive weight-lifting exercise.	BIS **Def. of subclinical BCRL**: Symptoms and BIS ratio >1.066 on dominant arm and >1.106 on non-dominant arm.	5Y	Surveillance group: n = 126 (32.3%) developed BCRL n = 101 were resolved/improved. Control group: n = 145 (45.7%) developed BCRL n = 30 were resolved/improved.

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
			BCRL ≥ stage 2 received CDT.			
Kaufman*[170] (2017)	Evaluation of clinical program	Women w any stage breast cancer. 15% had ALDN n = 206	**Measurement protocol:** pre-surgery and post-surgery at 6 wks. and then 3-6M intervals. **Women w BCRL:** Compression for 4 wks. followed by BIS measurement.	BIS **Def. of subclinical BCRL**: L-DEX > 10 from pre-surgery **Def. of chronic BCRL**: No resolution from compression and in need for complex decongestive physiotherapy (CDP)	25.9M	n = 21 (9.8%) developed BCRL Median time to resolution of BCRL: 1.9M (4.3M for women w ALDN, 1.4M for women w SLNB). No cases of chronic BCRL requiring CDP
Whitworth*[171,186]	Evaluation of clinical program	Women w unilateral breast cancer and ALND n = 93	**Measurement protocol:** pre-surgery and post-surgery at 1wk., 3, 6, 9, 12, 18, 24M **Women w BCRL:** Compression for 4 wks. followed by BIS measurement	BIS **Def. of BCRL**: L-DEX > 10 from pre-surgery **Def. of chronic BCRL**: No resolution from compression and in need for complex decongestive physiotherapy (CDP)	24M	n = 33 (35.4%) developed BCRL n = 10 (10.8%) did not respond to compression and required CDP n = 3 (3%) had unresolved BCRL
Koelmeyer[176] (2018)	Retro. cohort comparing "early surveillance" vs. "traditional referral-based"	Women w unilateral early stage breast cancer. 64% had ALND	**Measurement protocol:** Surveillance: pre-surgery or within 90 days of surgery	BIS **Def. of BCRL**: L-DEX > 10 from pre-surgery or	8M for surveillance group 2M for referral group	BCRL was identified earlier in surveillance than referral group

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
		Surveillance n = 188 Referral n = 285	Referral: > 90 days post-surgery **Women w BCRL:** Education, monitoring, "clinical management", exercises	outside normal range ±10		39% in referral and 14% in surveillance ($p < 0.01$) developed BCRL stage ≥ 1 24% in referral and 4% in surveillance ($p < 0.01$) developed BCRL stage ≥ 2
Kilgore[172] (2018)	Evaluation of clinical program	Women w unilateral breast cancer and ALND, radiation and/or taxane chemotherapy n = 146	**Measurement protocol:** pre-surgery and post-surgery at 3, 6, 12, 18, 24, 36, 48M **Women w BCRL:** compression and self-massage for 4-6 wks.	BIS **Def. of BCRL**: L-DEX > 10 from pre-surgery	21M/20M for participants w and w/t BCRL	n = 49 (34%) developed BCRL Of these n = 40 (82%) were resolved n = 9 (6%) developed chronic BCRL
Zou[187] (2018)	Pro. cohort	Women w unilateral early stage breast cancer. 323 (84%) had ALND n = 387	**Measurement protocol:** pre-surgery and post-surgery at 1, 3, 6, 12, 18, 24M **Women w BCRL:** NR	CIR and symptoms questionnaire **Def. of BCRL**: ≥2 cm at any point from pre-surgery	24M	Circumference detected n=114 (29.4%) with BCRL Questionnaire detected n = 126 (32.5%) with BCRL
Upper-body issues (ROM, muscle strength, function, pain, tightness)						
Springer[136] (2010)	Pro. cohort	Women w early stage breast cancer. 70% had ALND n = 94	**Measurement protocol:** pre-surgery and post-surgery at 1, 3, 6, 12 months **Everybody**: rehab program and education material about BCRL. **Women w issues**: individualized home-program.	ROM: goniometer Strength: MMT Pain: NRS ADL: home-made Arm Disability Questionnaire **Def. of issues**: "moderate-severe shoulder impairments"	12M	ROM: ND (returned to pre-surgery levels) Strength: ND ADL: 89-98% reported no functional difficulty.

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
Singh[180] (2013)	Quasi-experimental	Women w any stage breast cancer. 54/74% had ALND. Surveillance n = 41 Control n = 31	**Measurement protocol:** pre-surgery and post-surgery at 1, 6, 7 months **Everybody**: rehabilitation program and education material about BCRL. **Women w issues**: individualized rehab until issues were resolved.	ROM: goniometer Strength: MMT Pain: VAS ADL: DASH BCRL: CIR QoL: FACT-B+4 **Def. of issues**: ROM ≥10° Strength: one grade using MMT BCRL: >2cm at one point Poor posture	7M	26.8% vs 32.3% had upper-body issues, p = 0.62. 2.5% vs 9.7% had BCRL p = 0.19 ROM: surveillance group returned to pre-surgery levels while the control group had a decrease in flex ROM of -6.1˚±14.9. ND in other outcomes.
Lai[118] (2016)	Evaluation of clinical program	Women w early stage breast cancer. 29% had ALND n = 120	**Measurement protocol:** pre-surgery and post-surgery at 2-4 wks., 6 wks., 3, 6, 9 and 12 months **Everybody**: rehab program and education material about BCRL. **Women w issues**: manual therapy, home-program, BCRL treatment.	Pain: NR ROM: NR BCRL: CIR ADL: UEFI, QuickDASH **Def. of issues**: BCRL >3% ROM >20˚ "Presence of significant pain/activity limitations".	NA	33% were identified with issues. Most commonly BCRL.
Rafn[179] (2018)	RCT	Women w early stage breast cancer. 34% had ALND Surveillance n = 19 Control n = 21	**Measurement protocol:** pre-surgery and post-surgery at 3, 6, 9 and 12 months **Women w issues**: Individualized rehab incl. manual therapy,	ROM: goniometer Strength: HHD ADL: UEFI BCRL: perometer QoL: FACT-B+4 **Def. of issues**:	12M	No difference in prevalence of issues btw groups, p = 0.62. Surveillance: 53% Control: 44%

Author (year)	Design	Population Sample size	Intervention	Outcome measures	Follow-up	Results
			exercises and BCRL treatment as needed	One or a combination of: ROM ≥10% Strength: ≥25% ADL: ≥ 10 points BCRL: ≥200 mL **Complex issues:** ≥2 issues		↓ Complexity of issues in surveillance group, p = 0.04

Legend: ADL: activities of daily living. ALND: axillary lymph node dissection. BCRL: breast cancer-related lymphedema. BCS: breast conserving surgery. BIS: bioimpedance. Btw: between. CIR: circumference. Def.: definition. L-DEX: lymphedema index. M: month. MMT: manual muscle testing. NA: not applicable. ND: no difference between groups or from pre-surgery. NM: not mentioned. NRS: numerical rating scale. Post-op: post-operative. Pro: prospective. QoL: quality of life. QuickDASH: short form of Disability of Arm and Shoulder and Hand (DASH). Rehab: rehabilitation. Retro: retrospective. ROM: range of motion. Sur: surveillance. UEFI: upper extremity functional index. VAS: visual analogue scale. wk(s): week(s)

1.5.3.2 Self-management

Another approach for delivery of rehabilitation is self-management[188]. Self-management is defined as "the systematic provision of education and supportive interventions by healthcare staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support"[189]. As such, self-managed rehabilitation (goal setting, development of rehabilitation program, and outcome measurement) is performed in collaboration between the rehabilitation professional and patient supported by relevant resources (i.e., multimodal educational resources, self-tests to evaluate response to rehabilitation)[190]. With this approach, informed and engaged patients who are equipped to manage their own health and side-effects from treatment are thought to achieve better clinical outcomes than patients who passively receive care from healthcare professionals[191]. Self-management programs have been shown to be highly acceptable for people with chronic conditions[192], and cost-effective[193,194] by reducing hospital admissions, hospital readmissions and risk of future complications. Specific to BCSs, self-management programs have primarily been developed to support physical activity or psychological adjustment[195–197]. Thus, a 2016 systematic review of 13 RCTs reported improved health-related quality of life with self-management programs to support physical activity during or after treatment for breast cancer[198]. British Columbia Ministry of Health has implemented a number of self-management programs for people with chronic conditions[191], however a self-management program to support upper-body surveillance and rehabilitation for BCSs has yet to be developed. A self-management approach may be particularly suitable for prospective surveillance for BCRL due to the potentially variable and protracted time to onset of the condition.

1.5.4 Health Behavioural Theories

Breast cancer survivors are recommended to perform upper-body rehabilitation for months during and after treatment for breast cancer which requires them to adopt and maintain new behaviours. However, obtaining patient adherence to home-based interventions is challenging and decreases with time[199]. Identification of key theoretical determinants of adherence to self-managed rehabilitation or surveillance may be useful to guide the development or modification of existing rehabilitation programs for BCSs.

There are no theories of adherence per se, but numerous models or theories from the literature in health psychology are useful in understanding adherence to upper-body rehabilitation prescriptions. The most commonly investigated theories of health behaviour change are the Health Belief Model (HBM), the Protection Motivation Theory, the Theory of Reasoned Action, the Theory of Planned Behavior (TPB), the Social-Cognitive and Self-efficacy Theory, the Transtheoretical Model of Behaviour Change (stages of change), Self-Regulation Model (SRM)[200], and the Health Action Process Approach[201]. These theories share common assumptions that are characteristic of cognitive-behavioural theories: that people are 1) able to plan and use decision making processes (cognitive), and 2) goal directed and self-regulating[202]. Both assumptions emphasize the active role of the person and that a cognitive process is preceding behaviour. The social interpersonal environment is thought to influence behaviour, however, less emphasis is put on the influence of the physical environment (community, public policy, institutional). As such, the theories are focused on (and make predictions about) the behaviour of an individual person and are thereby less focused on health behaviour patterns of a population. Further, the theories are generic, developed to explain any health behaviour (i.e., smoking cessation, wearing a seat belt) and are not specifically designed to capture the unique

existential aspects of getting a life-threatening disease or living and managing a chronic condition (i.e., BCRL). Consequently, any one theory may explain some but not all of the variability of self-managed surveillance and rehabilitation behaviour.

In relation to understanding motivation to performing rehabilitation exercises after surgery for breast cancer, the TPB may be useful. Key constructs in TBP are *behaviour* and *intentions*, which are functions of three determinants[197]: 1) a *personal* determinant is the individual's *attitude towards a behaviour;* the positive or negative evaluations of performing the particular behaviour. Attitudes can either be instrumental (upper-body rehabilitation is good for me) or affective (I enjoy performing the rehabilitation exercises). 2) A *social* determinant is the pressure from friends or family to perform or not to perform a particular behaviour. This factor is termed *subjective norm* as it deals with perceived normative expectations about what others do (descriptive component) or what others think (injunctive component). The descriptive component will likely not play a role in motivation to upper-body rehabilitation, as the family/friends will not perform the rehabilitation themselves, however the injunctive component may be key. 3) A *control* determinant is the sense of self-efficacy termed *perceived behavioural control* and is defined as "the perceived ease or difficulty of performing the behavior"[203]. According to TPB, a behaviour is generally performed when a person evaluates it as positive, when they experience social pressure to perform it, and when they believe they have the means and opportunity to do so. TPB is validated in measuring motivation for exercise among cancer survivors including BCSs and is considered a good theoretical framework to explain the effectiveness of physical activity interventions and identify predictors for behaviour change[204–206]. While numerous studies have utilized TPB to investigate adherence to general supervised exercise in BCSs during[207,208] and after[205,209–214] treatment, only few studies have used TPB in

home-based interventions[215–218], and no study have employed TPB to understand adherence to home-based upper-body rehabilitation among BCSs.

In relation to a secondary preventative behaviour, such as self-measurement for BCRL, the belief and attitude model, Health Belief Model (HBM) may be useful in understanding the determinants. The HBM proposes that the likelihood of performing self-measures of arm circumference is determined by: 1) a level of knowledge about how to perform such behaviour, and that the women; 2) view themselves as potentially vulnerable to getting BCRL; are 3) convinced of the efficacy of early detection of BCRL; and 4) foresee few barriers in performing the self-measures of arm circumference. These factors are then mediated by the women's demographics and cues to action (i.e., reminder to perform self-measures). Thus, according to the behavioural theories discussed here, by promoting self-managed care, the intended rehabilitation or surveillance behaviour has better odds of being maintained and thus better outcomes in upper-body function are expected.

1.6 Dissertation Objectives

In this body of work, two questions guided the development of hypotheses and research questions and choice of scientific approaches. First, we wondered why so many women develop chronic upper-body issues following treatment for breast cancer, despite the well-documented benefits of physical rehabilitation to address these issues. Secondly, we wondered how to facilitate early detection of issues and equal access to evidence-based physical rehabilitation and whether changes should be made to the current delivery of care to address the high prevalence of chronic breast cancer-related upper-body issues. The overall objective of this dissertation is therefore to inform strategies to improve the reach of and timely access to quality physical

rehabilitation in women with breast cancer. The central hypothesis is that early detection and timely physical rehabilitation will decrease the prevalence of chronic breast cancer-related upper-body issues. This work will utilize different scientific approaches (quantitative and qualitative), and follow principles that we believe are important, namely to: 1) engage diverse populations; 2) extend research beyond metropolitan areas; 3) address clinical practice in multiple jurisdictions; and 4) learn from many voices. This work is the first to utilize, and combine, the prospective surveillance model and self-management and move towards a self-managed surveillance and rehabilitation approach for upper-body issues. It has the potential to advance the field of oncology rehabilitation research and care by: 1) expanding our knowledge about current upper-body rehabilitation care for BCSs and identify areas for improvement; 2) developing patient-administered outcome measures to aid BCSs in identifying the development or progression of upper-body issues; and 3) modernizing rehabilitation care by introducing technology-supported resources to aid PTs and BCSs in prescribing and performing self-managed upper-body rehabilitation.

Primary objectives of this research are:

1. To develop self-management resources for women to engage in standard of care post-operative rehabilitation exercises and evaluate the feasibility of using these in community-based rehabilitation centres in a Danish context (Chapter 2).
2. To develop resources for self-measurement of arm circumference and test the reliability, validity and motivation among women with and without BCRL in the laboratory setting (Chapter 3).
3. To test the feasibility and reliability of self-managed surveillance for upper-body issues among women scheduled for surgery for breast cancer in the clinical setting (Chapter 4).

4. To explore the perspectives among BCSs, rehabilitation professionals and breast surgeons on public rehabilitation services in British Columbia, including preferences for rehabilitation care delivery and attitudes towards self-managed surveillance and rehabilitation (Chapter 5).

Chapter 2: Development and Evaluation of The Breast Cancer Online Rehabilitation (BRECOR) Program for Self-managed Upper-body Rehabilitation for Women with Breast Cancer

2.1 Synopsis

Physical rehabilitation is recommended for BCSs, but development of new delivery approaches that are clinically feasible and acceptable are needed to reduce access barriers to care and enhance rehabilitation outcomes. In addition, resources to assist PTs in the clinical decision-making around the prescription of upper-body rehabilitation are needed. This study aimed to develop and evaluate a rehabilitation program (BRECOR) to support self-managed upper-body rehabilitation after surgery for breast cancer. Development of the three program elements (clinical assessment tool, education pamphlet, and website) was informed by 17 PTs with experience in oncology rehabilitation and 10 women with breast cancer. Feasibility was evaluated by 35 women who had recently undergone surgery for breast cancer and 29 women who had completed surgery and radiation therapy for breast cancer. Participants performed an individualized 12-week self-managed upper-body rehabilitation program informed by the clinical assessment tool, with support from the education pamphlet and website. Outcomes included recruitment and retention rates, adherence, capacity in terms of time by the PTs to deliver the program, participant satisfaction and upper-body functioning. Results generally support the benefit of the program with good recruitment, retention, and adherence to the self-managed upper-body rehabilitation program. Participants improved their upper-body function and reported benefit from the program. The BRECOR program elements provide a toolkit to enforce qualified

upper-body assessment, rehabilitation prescriptions and support self-managed upper-body rehabilitation after treatment for breast cancer. However, the effectiveness of the program in improving upper-body function cannot be determined as this was a single-group feasibility study.

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2.2 Introduction

Breast cancer is the most common malignancy among women in the world[1]. While survival has improved substantially, BCSs are at risk of developing upper-body issues after treatment[219]. Even five years post-surgery, approximately 68% of BCSs report upper-body pain, 72% have tightness in the area of surgery[48,49], 67% have limited shoulder ROM[47–49], 60% have impaired muscular strength[48,49,55], and 20% develop BCRL[78,220,221]. While the effectiveness of physical therapy to restore upper-body functioning is well established[82,86,222], health care systems in Europe and North America face increasing challenges in providing cost-effective and high-quality rehabilitation[223]. These challenges include the rising costs of overall cancer care and mandate to ensure equitable access to care.

Disparities in access to oncology rehabilitation for BCSs is identified to cause underutilization of existing services[224] and greater risk of development of chronic upper-body issues[225]. The patient-level barriers to access to see a PT include time, any related out-of-pocket

costs and cost or logistics of transportation[226]. At the health system-level, lack of oncology rehabilitation programs and PTs with the knowledge, skill, and experience to safely and effectively treat cancer-related impairments hinders timely treatment[156,227,228]. Both patient-level and health system-level access barriers often disproportionally affect patients of lower socioeconomic status[225] or those living in rural areas. To improve access to high-quality care, the Danish National Clinical Guideline[229] highlighted the need for development of innovative rehabilitation programs that can be delivered across settings.

Based on access challenges, promoting the engagement of BCSs in self-management has become a priority of cancer care initiatives[230,231], including testing self-management models to prevent or manage upper-body issues[232]. Research studies on rehabilitation programs supported by web-based self-management resources demonstrate a benefit on upper-body function and reduce pain among BCSs[233]. In addition to providing written material, supportive video guides or verbal instructions have been suggested as relevant to facilitate long-term rehabilitation behavior[234] and improve clinical outcomes in upper-body function. Furthermore, home-based approaches may assist with patient-level barriers around time, cost and rural or remote locations[235]. However, novel approaches to guide BCSs in self-managed upper-body rehabilitation at home have not been broadly translated into current clinical care. There is a need to develop new approaches to support self-managed rehabilitation that are clinically feasible and acceptable to reduce barriers to care and enhance rehabilitation outcomes. In addition, resources to assist PTs in the clinical decision-making around the prescription of upper-body rehabilitation are needed.

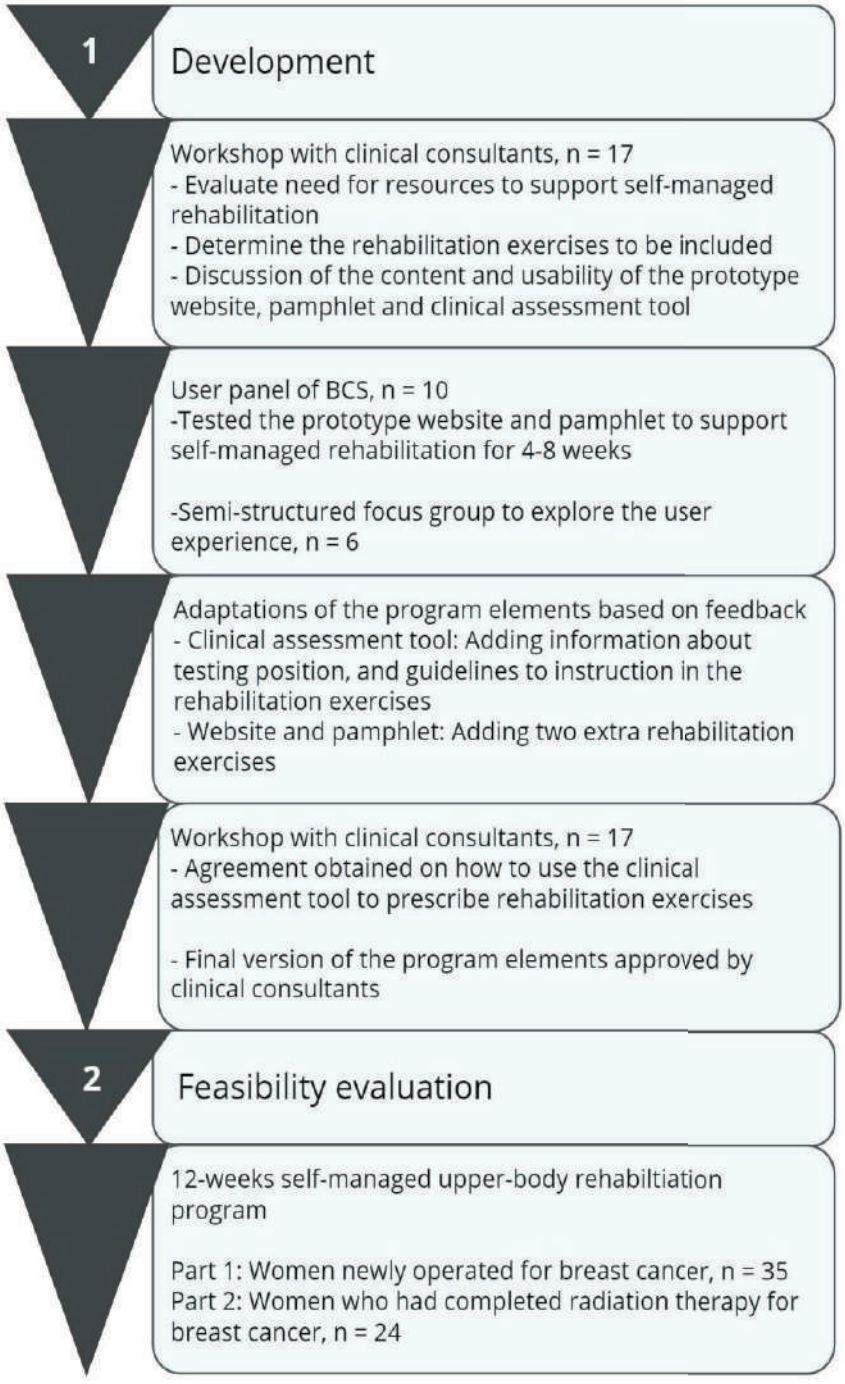
This chapter reports on the development and feasibility evaluation of the Breast Cancer Online Rehabilitation (BRECOR) program to support self-managed upper-body rehabilitation in BCSs.

2.3 Methods

2.3.1 Study Design

The study was conducted in two stages: 1) Program development which included content development, prototype design and revisions; and 2) Feasibility evaluation of the BRECOR program in 11 municipalities in Denmark (Figure 2.1).

Figure 2. 1 Process of developing and feasibility evaluation of a self-managed program for upper-body rehabilitation for women with breast cancer



2.3.2 Program Development

Program content and elements were developed by the project team, clinical consultants, and patient representatives. Clinical consultants (the PTs who manage community-based oncology rehabilitation in the Capital Region of Denmark, n = 17) participated in two workshops and completed questionnaires to evaluate the need for a self-managed upper-body rehabilitation program for BCSs, and discuss the content, relevance and usability of the BRECOR program elements. A convenient sample of ten BCSs, who were receiving rehabilitation at one of the rehabilitation centres, served as patient representatives and formed a user panel. The user panel was given the pamphlet and access to the prototype website for 4-8 weeks to perform rehabilitation exercises at home and completed a questionnaire on usability of the resources. Further, a semi-structured focus group was conducted with a convenient sample of participants from the user panel (n = 6) to explore the user experience, perceived benefit, strengths and weaknesses of the program.

Suggestions from the user panel led the team to adjust the website to include more features, such that it functioned as a single location for all relevant information. Videos to demonstrate self-managed manual lymph drainage were added, along with mindfulness audio files, written information about BCRL, and written testimonies of other women's experiences about going through treatment for breast cancer. Input from the clinical consultants led the team to adjust the clinical assessment tool, specifically adding information on correct testing positions for some of the assessments and guidelines for how to teach the rehabilitation exercises, along with the addition of two rehabilitation exercises on the website and pamphlet. During the second workshop, agreement was obtained among the clinical consultants on how to use the clinical

assessment tool that, for example, limitations in shoulder ROM, would trigger a prescription of rehabilitation exercises to improve joint mobility, while pain and tightness from scar tissue in the breast region would trigger a prescription for self-massage. The updated version of the program elements was then presented to the clinical consultants at the second workshop who unanimously reported in a questionnaire that the program elements could be tested for feasibility at their rehabilitation center.

2.3.3 Program Description

The final BRECOR program consists of: 1) a clinical assessment tool to assist PTs in their examination and to inform a prescription of rehabilitation exercises (Appendix A); 2) a website with videos of rehabilitation exercises to support BCSs in performing these at home[236]; and 3) an education pamphlet with the same rehabilitation exercises as the website, here described in text with photos (Appendix B) (Table 2.1). The rehabilitation exercises are upper-body mobility and strength exercises that are recognized as the appropriate rehabilitation for BCSs in Scandinavia[237,238].

The website[236] is organized with specific rehabilitation exercises depending on the type of surgery; lumpectomy or mastectomy. For each surgery type the website includes: 1) videos with verbal introductions on the benefits of performing upper-body rehabilitation and what to expect during radiation therapy; 2) information from a multi-disciplinary team that answers common concerns (i.e., diet, sick leave regulations, physical activity, symptom management, and counseling resources); and 3) twenty-four videos of rehabilitation exercises that guide the performance of the exercises or activity in the correct pace and provide information about red flags, as well as ways to progress or regress (Table 2.1). For example, for each surgery type the

website provides video guides that features women who have undergone the specific type of surgery who demonstrate tissue flexibility on the operated breast, perform self-managed nerve tissue stretches, or perform rehabilitation exercises for joint mobility or muscle strength.

Table 2. 1 Elements in the BRECOR program

Program element	User	Description
Clinical assessment tool	Physical therapists	Tool to support the assessment of upper-body impairment including: - active shoulder joint mobility using a goniometer - muscular strength using manual muscle testing - pain and tightness using a numeric pain rating scale Inform the prescription of rehabilitation exercises
Website	Women with breast cancer	Information about benefits of rehabilitation Information from multi-disciplinary team Video guides, n = 24: - self-massage of scar tissue, n = 5 - rehabilitation exercises, n = 11 - self-managed manual lymph drainage, n = 4 - yoga and relaxation, n = 4 Mindfulness sound files for stress-management, n = 3
Education pamphlet	Women with breast cancer	Information about common upper-body issues and recommendations for how to perform rehabilitation exercises Photos and text illustrating: - self-massage of scar tissue, n = 5 - rehabilitation exercises, n = 11 - self-managed manual lymph drainage, n = 4

2.3.4 Feasibility Evaluation

We conducted a single-group, 12-week feasibility study of the BRECOR program in 11 municipalities in Denmark. The study was conducted in two parts to evaluate feedback from BCSs who had recently undergone surgery for breast cancer (Part 1), and BCSs who had completed surgery and radiation treatment for breast cancer (Part 2). The study was approved by

the Danish Ethics Board (H-15017482), the University of British Columbia Clinical Research Ethics Board (H15-03270), the Danish Data protection Agency (File number: 2015-55-0736), and registered at ClinicalTrials.gov (ID: NCT02752659).

2.3.5 Participants

Women were eligible if they were 18-80 years, have undergone any type of surgery for any stage of breast cancer and referred to rehabilitation at one of the study centres. For Part 1, participants had to be within 8 weeks of surgery. For Part 2, participants had to have completed radiation therapy within the last 6 weeks (which is commonly started 9 months post-surgery). Participants also had to have access and ability to use the internet, and ability to read and understand Danish. Women were excluded if they had surgery for breast cancer with immediate breast reconstruction (i.e., different rehabilitation needs due to more extensive surgery), or other serious illness that prohibited participation (i.e. mental illness or illness requiring surgery within the study period). All patients referred for rehabilitation during the study period were screened for eligibility. Participants for Part 1 were recruited consecutively during a 10-week period from January to March 2016, while participants for Part 2 were recruited consecutively during a 20-week period from June to October 2016. All participants provided written informed consent prior to enrolment.

2.3.6 Assessment Procedures

At baseline, participants underwent an assessment, guided by the clinical assessment tool, by a PT at the rehabilitation centre in the municipality of their residence. The assessment included measures of shoulder ROM, arm circumference, upper-body muscle strength, and pain

and tightness in the breast region. Each participant was given the education pamphlet, in which the PT marked the rehabilitation exercises specifically recommended for the individual. In addition, participants were verbally introduced to the website, including the videos for the prescribed rehabilitation exercises, and when possible, the PT demonstrated the navigation of the website. At the 12-week follow-up, the clinical assessment was repeated for participants in Part 1 but not in Part 2 due to resource constraints as these participants had completed treatment and were usually no longer seen for rehabilitation at the centres. While the clinical assessment at baseline is needed to inform the rehabilitation prescription, the follow-up assessment was performed to collect study outcomes is not a key component of the BRECOR program. The PTs, who performed the follow-up assessments, were blinded to baseline measures.

2.3.7 Intervention

The 12-week self-managed upper-body rehabilitation program was prescribed at the face-to-face baseline assessment by the PT based on the individual need. All PTs who delivered the program had experience in oncology rehabilitation and had attended the two workshops prior to study start where the program resources were reviewed and agreement was obtained about how to use the resources and prescribe the self-managed program. A typical prescription included three rehabilitation exercises that should be performed ≥ 4 times weekly at home with the support from the website and education pamphlet with duration of approximately 20 minutes per session. If needed, the PTs could adapt the rehabilitation prescription during the study when the participant was seen for treatment as part of usual care. The BRECOR program resources were offered in addition to usual care at the centres. Usual care differed from site to site but generally included a combination of group-based rehabilitation sessions specific for BCSs, individual

manual treatment, and participation in generic group-based exercise sessions with people with other types of cancers or conditions.

2.3.8 Outcome Measures

2.3.8.1 Feasibility Outcomes

Recruitment rate, retention rate, adherence, safety, capacity and participant satisfaction were collected in agreement with the recommendations for feasibility studies[239]. Recruitment rate was calculated as the proportion of included participants relative to the number of eligible BCSs. Patients who did not complete the baseline questionnaires were not enrolled. The retention rate was calculated as the proportion of enrolled participants who completed the follow-up assessment (Part 1) or questionnaire (Part 2). Feasibility was defined *a priori* as retention of ≥ 90%.

Adherence was determined by either 1) a logbook, 2) tracking the use of the website, or 3) a questionnaire. Adherence was calculated as the proportion of participants who performed the program ≥ 4 times weekly and feasibility was defined *a priori* as ≥ 75%. The number of times and the duration a participant was logged onto the website was tracked by Google Analytics. Safety was determined using the logbook. Participants were encouraged to report pain/discomfort during or following the rehabilitation exercises and reasons for discontinuing the program.

Capacity was defined as the time spent by the PT with each participant to complete assessments, instruction of the program and introduction to the website.

Participant satisfaction was collected by questionnaire at follow-up (Appendix C). Feasibility was defined *a priori* as ≥ 75% reporting to be "very/somewhat satisfied" with the program.

2.3.8.2 Explorative Outcomes

To understand motivation related to the performance of self-managed upper-body rehabilitation, the participants' initial reaction to the program, intended use of the materials, and perceived importance of performing rehabilitation exercises was collected at baseline. We developed a questionnaire based on the Theory of Planned Behavior (TPB), which has been used in previous research examining health behaviors among BCSs[204–206], and adapted the items to assess motivation for self-managed upper-body rehabilitation. The 19-items used a 7-point Likert scale with higher scores indicating greater motivation (Appendix D).

Upper-body impairment was evaluated in Part 1 by PTs and included: 1) active shoulder ROM for flexion and external rotation; 2) muscle strength using Manual Muscle Testing; 3) pain and tightness using a 0-10 Numeric Pain Rating Scale. For shoulder ROM and muscle strength, a three-level categorical outcome was applied (not limited, moderately limited, or greatly limited). Finally, self-reported upper-body function using the QuickDASH was collected in Part 1 and 2.

2.3.9 Statistical Analysis

Participant characteristics were summarized using descriptive statistics and presented as mean and standard deviations (SD) or frequency counts. Wilcoxon Signed-Rank Test and paired t-test evaluated the changes from baseline to follow-up for categorical and continuous variables,

respectively. Bivariate logistic regression tested the prediction of motivation on adherence. The analyses were two-sided and carried out using the IBM SPSS™ version 23.0.

2.4 Results

2.4.1 Feasibility Outcomes

Of 67 women referred to rehabilitation for Part 1, 44 (65.7%) were eligible and 39 (88.6%) consented to participate. The primary reasons for ineligibility were having no access to the internet and being older than 80 years (Figure 2.2). Four patients (10.3%) did not complete the baseline questionnaires and were not enrolled. Among the 35 participants enrolled (recruitment rate of 79.5%), 29 participants completed the follow-up assessment (retention rate of 82.9%).

Of 30 women referred to rehabilitation for Part 2, 28 (93.3%) were eligible, and 26 (92.9%) consented to participate. Two patients (7.7%) did not complete the baseline questionnaires and were not enrolled. Among the enrolled 24 participants (recruitment rate of 85.7%), 20 participants completed the follow-up questionnaire (retention rate of 83.3%).

Most participants were well-educated and lived in Copenhagen (Table 2.2). Ten (20%) participants returned the logbook at follow-up which precluded its use to establish adherence and to monitor safety. Further, not all participants used the website and tracking its use had limited utility as a measure for adherence. One third of participants did not login to the website once with the primary reasons being “no need” or “forgot about it”. The mean number of logins was 2.45 and 0.53 per participant in Part 1 and Part 2, respectively. Participants spent a mean of 7.04 minutes and 5.22 minutes per login in Part 1 and Part 2, respectively. In contrast, 17 (59%) and 8 (40%) participants in Part 1 and 2, respectively, reported to have used the education pamphlet

"much/very much" (Table 2.3). Adherence was therefore calculated using one item on the follow-up questionnaire: "During the past 12-weeks, on average how many times have you performed the home-based program?". Adherence to the program was 72% in Part 1 and 45% in Part 2 (Table 2.3). Most participants did not report having any barriers to performing the program, however, five (25%) participants in Part 2 reported that it took too much time to complete.

In terms of capacity for Part 1, the time commitment for PTs (face-to-face time with participants during the clinical assessment and introduction to the website, followed by documentation) was 92.4 ± 27.1 minutes at baseline, and 54.2 ± 12.7 minutes at follow-up. Twenty-six (90%) participants in Part 1 and 14 (70%) in Part 2 reported to have benefitted "much/very much" from performing the program. Satisfaction with the program was reported by 16 (55%) and 12 (60%) participants in Part 1 and 2, respectively.

Figure 2. 2 Flow of participants

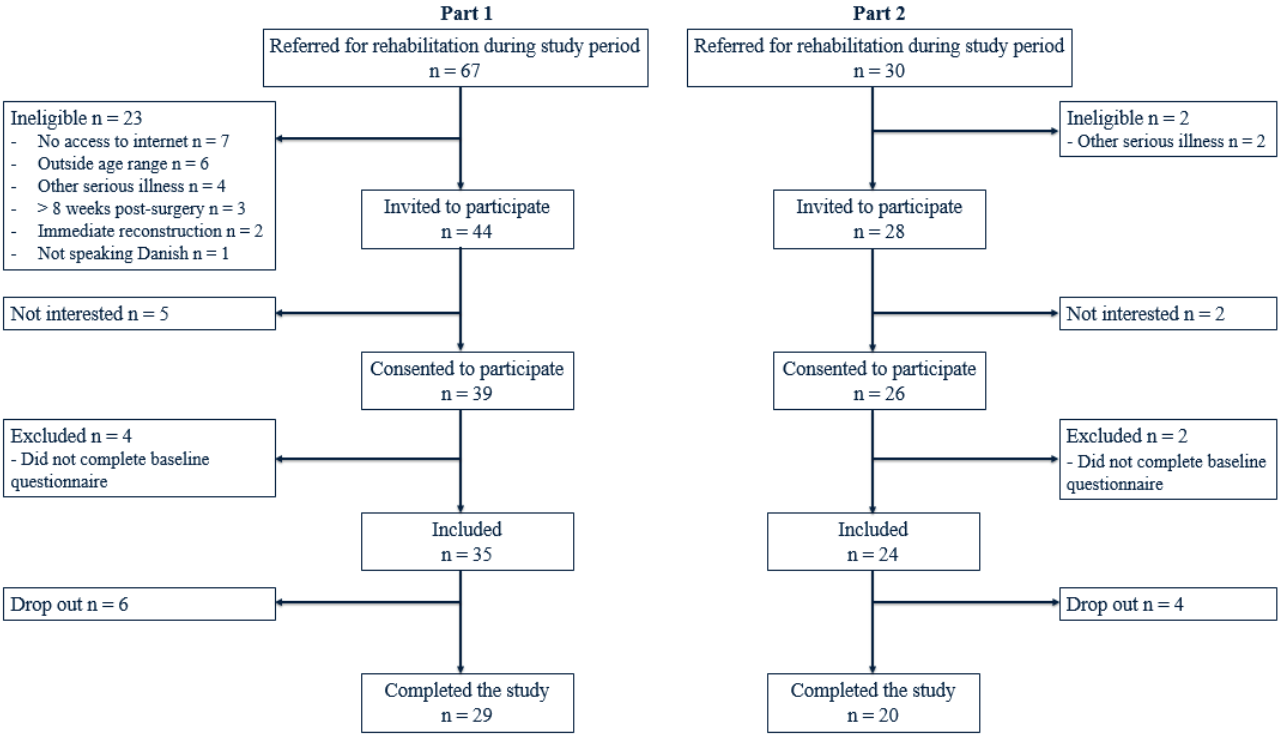


Table 2. 2 Participant characteristics

	Part 1 n = 35	**Part 2** n = 24
Age, mean years (SD)	60.6 (11.6)	55.0 (9.9)
Nationality, n (%)		
Danish	33 (94.3)	23 (95.6)
Other	2 (5.7)	1 (4.2)
Education, n (%)		
High school or less	4 (11.4)	1 (4.2)
Technical degree	7 (20.0)	6 (25.0)
Bachelor degree	13 (37.1)	10 (41.7)
Graduate degree	11 (31.4)	7 (29.2)
Work, n (%)		
Retired	15 (42.9)	6 (25.0)
Currently working	16 (45.7)	16 (66.7)
Unemployed/student	4 (11.4)	2 (8.3)
Social support, n (%)		
Living alone without children	7 (20.0)	6 (25.0)
Living alone with children	2 (5.7)	2 (8.3)
Married/common law without children	14 (40.0)	9 (37.5)
Married/common law with children	10 (28.6)	7 (29.2)
Other	1 (2.9)	0 (0)
Surgery type, n (%)		
Lumpectomy and SLNB	5 (14.3)	3 (12.5)
Lumpectomy and ALND	13 (37.1)	10 (41.7)
Mastectomy and SLNB	11 (31.4)	1 (4.2)
Mastectomy and ALND	6 (17.1)	9 (37.5)
Number of dissected lymph nodes, mean (SD)	13.66 (10.9)	12.36 (10.4)
Number of positive lymph nodes, mean (SD)	2.51 (4.1)	0.84 (1.1)
Time since surgery, mean days (SD)	26 (12)	215 (122)
Adjuvant therapy, n (%)		
Chemotherapy	18 (62.1)	6 (25.0)
Radiation	19 (65.5)	24 (100)
Anti-hormonal therapy	26 (89.7)	7 (29.2)
Herceptin	6 (20.1)	-

Table 2. 3 BRECOR program usability and satisfaction

	Part 1 n = 29	**Part 2** n = 20
Participant satisfaction and adherence		
Satisfaction with program, n (%)		
Very/somewhat unsatisfied	1 (3.4)	0 (0)
Neutral	11 (37.9)	4 (20.0)
Very/Somewhat satisfied	16 (55.2)	12 (60.0)
No response	1 (3.4)	4 (20.0)
Benefit from program, n (%)		
No/little	3 (10.3)	1 (5.0)
Neutral	4 (13.8)	2 (10.0)
Much/very much	26 (89.7)	14 (70.0)
No response	0 (0)	3 (15.0)
Self-reported adherence, n (%)		
≤ 1 time/week	4 (13.8)	5 (25.0)
1-3 times/week	4 (13.8)	6 (30.0)
≥ 4 times/week	21 (72.4)	9 (45.0)
Barriers for performing program		
No barriers	18 (62.1)	9 (45.0)
Feeling lonely	3 (10.3)	1 (5.0)
The program took too much time	2 (6.9)	5 (25.0)
Inconvenient	1 (3.4)	2 (10.0)
Needed peer-support	1 (3.4)	2 (10.0)
Website		
Benefit from website, n (%)		
No	6 (20.7)	3 (15.0)
A little	5 (17.2)	5 (25.0)
Neutral	5 (17.2)	3 (15.0)
Much/very much	12 (41.4)	5 (25.0)
No response	1 (3.4)	4 (20.0)
Easy to navigate website, n (%)		
No	1 (3.4)	1 (5.0)
Neutral	11 (37.9)	5 (25.0)
Yes	15 (51.7)	10 (50.0)
No response	0 (0)	4 (20.0)
The rehabilitation videos were relevant, n (%)		
No	0 (0)	0 (0)
Neutral	8 (27.6)	5 (25.0)
Yes	18 (62.1)	10 (50.0)
No response	3 (10.3)	5 (25.0)
Number of website logins, n (%)		
None	9 (31.0)	7 (36.0)
1-3 times	6 (20.7)	4 (20.0)
3-4 times	5 (17.2)	4 (20.0)
≥ 5 times	9 (31.0)	4 (20.0)
No response	0 (0)	1 (5.0)
Reasons for no login, n (%)		
No need	6 (20.7)	2 (10.0)
Too busy	1 (3.4)	1 (5.0)
IT issues	2 (6.9)	0 (0)

	Part 1 n = 29	**Part 2** n = 20
Illness	0 (0)	1 (5.0)
Forgot about it	0 (0)	3 (15.0)
Website helped perform the rehabilitation correctly, n (%)		
No	6 (20.7)	3 (15.0)
A little	3 (10.3)	3 (15.0)
Neutral	3 (10.3)	3 (15.0)
Much/very much	16 (55.2)	7 (35.0)
No response	1 (3.4)	4 (20.0)
Pamphlet		
Use of pamphlet, n (%)		
No	3 (10.3)	4 (20.0)
A little	9 (31.0)	4 (20.0)
Neutral	0 (0)	2 (10.0)
Much/very much	17 (58.6)	8 (40.0)
No response	0 (0)	2 (10.0)
Capacity		
Baseline, minutes, mean (SD)		
Clinical assessment	48.8 (14.3)	
Introduction to website	16.4 (7.5)	-
Documentation	26.2 (16.2)	
Total time spent per participant	92.4 (27.1)	
Follow-up, minutes, mean (SD)		
Clinical assessment	35.2 (9.5)	
Introduction to website	7.6 (6.1)	-
Documentation	11.7 (5.0)	
Total time spent per participant	54.2 (12.7)	

2.4.2 Explorative Outcomes

For Part 1, three motivational constructs predicted adherence to the program: 1) instrumental attitude ($\beta = 2.48$, $R^2 = 0.34$, $p = 0.02$); 2) planning ($\beta = 0.46$, $R^2 = 0.21$, $p = 0.05$); and 3) subjective norm ($\beta = 0.94$, $R^2 = 0.22$, $p = 0.04$) (Table 2.4). For Part 2, no constructs predicted adherence. When the motivational data from Part 1 and 2 was merged, same three constructs predicted adherence. In Part 1, fewer participants presented with limited muscle strength and shoulder ROM at follow-up (Table 2.5). Further, upper-body tightness improved. Self-reported upper-body function improved for participants in Part 1 and 2, although the improvements were not significant.

Table 2. 4 Prediction of Theory of Planned Behavior constructs on adherence

	Internal consistency (α)	TBP Mean (SD)	Adherence n (%)	β	R^2	P-value
Instrumental attitude, three items						
Part 1	0.92	6.45 (0.54)	21 (72.41)	2.48	0.34	0.02*
Part 2	0.73	6.38 (0.42)	9 (45.00)	0.81	0.04	0.46
Merged	0.86	6.42 (0.49)	30 (61.22)	1.73	0.19	0.01*
Affective attitude, three items						
Part 1	0.88	4.82 (1.09)	21 (72.41)	0.45	0.06	0.27
Part 2	0.84	4.45 (1.15)	9 (45.00)	0.47	0.06	0.34
Merged	0.86	4.65 (1.12)	30 (61.22)	0.46	0.07	0.12
Intention, two items						
Part 1	0.09	-	-	-	-	-
Part 2	0.88	6.20 (1.12)	9 (45.00)	2.62	0.33	0.07
Merged	0.45	-	-	-	-	-
Planning, four items						
Part 1	0.93	5.69 (1.91)	21 (72.41)	0.46	0.21	0.05*
Part 2	0.97	5.16 (2.00)	9 (45.00)	0.59	0.23	0.11
Merged	0.95	5.46 (1.95)	30 (61.22)	0.51	0.22	<0.01*
Self-efficacy, two items						
Part 1	0.98	5.90 (1.46)	21 (72.41)	0.24	0.04	0.37
Part 2	0.98	5.46 (1.48)	9 (45.00)	0.43	0.10	0.25
Merged	0.98	5.70 (1.47)	30 (61.22)	0.36	0.09	0.09
Perceived behavioral control, two items						
Part 1	0.71	6.09 (1.21)	21 (72.41)	0.02	0.00	0.96
Part 2	0.66	5.26 (1.48)	9 (45.00)	0.32	0.06	0.35
Merged	0.66	5.71 (1.39)	30 (61.22)	0.29	0.05	0.19
Subjective norm, three items						
Part 1	0.91	6.34 (0.97)	21 (72.41)	0.94	0.22	0.04*
Part 2	0.94	5.90 (1.36)	9 (45.00)	0.60	0.15	0.17
Merged	0.93	6.14 (1.17)	30 (61.22)	0.81	0.21	0.01*

Table 2. 5 Upper-body impairment

	Baseline n = 35	Follow-up n = 29	P-value
Shoulder range of motion on surgery side			
Flexion, n (%)			
Not limited	19 (54.3)	27 (93.1)	
Moderately limited	13 (37.1)	1 (3.4)	< 0.01*
Greatly limited	1 (2.9)	0 (0)	
Missing	1 (2.9)	1 (3.4)	
External rotation, n (%)			
Not limited	17 (48.6)	21 (72.4)	
Moderately limited	11 (31.4)	6 (20.7)	0.03*
Greatly limited	3 (8.6)	1 (3.4)	
Missing	4 (11.4)	1 (3.4)	
Upper-body muscle strength on surgery side			
Latissimus dorsi, n (%)			
Not limited	25 (71.4)	25 (86.2)	
Moderately limited	9 (25.7)	1 (3.4)	0.01*
Greatly limited	0 (0)	0 (0)	
Missing	1 (2.9)	3 (10.3)	
Serratus anterior, n (%)			
Not limited	16 (45.7)	16 (55.2)	
Moderately limited	13 (37.1)	10 (34.5)	0.59
Greatly limited	1 (2.9)	1 (3.4)	
Missing	5 (14.3)	2 (6.9)	
Pectoralis major clavicular part, n (%)			
Not limited	13 (37.1)	17 (58.6)	
Moderately limited	18 (51.4)	8 (27.6)	0.01*
Greatly limited	0 (0)	0 (0)	
Missing	4 (11.4)	4 (13.8)	
Pectoralis major sternum part, n (%)			
Not limited	21 (60.0)	22 (75.9)	
Moderately limited	13 (37.1)	6 (20.7)	0.11
Greatly limited	0 (0)	0 (0)	
Missing	1 (2.9)	1 (3.4)	
Pain and tightness			
Pain, median (IQs)			
NRS (scores 0-10)	1.0 (1.0;3.0)	1.0 (1.0;2.0)	0.18
Tightness, median (IQs)			
NRS (scores 0-10)	4.0 (3.0;7.0)	2.5 (2.0;4.8)	<0.01*
Upper-body function			
QuickDASH, Mean (SD)			
Part 1	19.8 (13.3) n = 24	13.5 (15.8) n = 17§	0.08
Part 2	15.2 (14.8)	11.0 (8.2)	0.85

2.5 Discussion

The BRECOR program is a novel resource to assist PTs and BCSs in self-managed upper-body rehabilitation and has the potential to be widely disseminated. Based on the recruitment and retention rates, this program is feasible and of interest to most women in this study.

Overall, recruitment and retention rates were high, demonstrating an interest by women in receiving this type of program. Most participants adhered to the program, were satisfied with and expressed benefit from participating. We defined adherence as ≥ 75% of participants performing ≥ 4 sessions weekly. While few studies apply *a prior* thresholds for adherence, this threshold has been used previously in feasibility studies of self-managed exercise interventions[240]. The adherence in Part 1 was 72% which fell just below the *a priori* feasibility criteria, while participants in Part 2 had much lower adherence (45%). This study cannot determine the reasons for the low adherence in Part 2. While we anticipated that radiation therapy would be a point in the cancer treatment trajectory when upper-body issues may be prevalent, the length of time since the primary surgery may have reduced the perceived need by BCSs to engage in upper-body rehabilitation. Qualitative research is needed to fully understand this. Previous feasibility studies of self-managed programs among BCSs have reported adherence between 39% and 91%[241–243]. The difference in adherence originates in a diversity of decision-making when determining the frequency of performing a self-managed program and consequently in definitions for adherence employed. For example, Stan and colleagues report 39% adherence to a DVD delivered yoga program when defining adherence as performing ≥ 3 weekly sessions for ≥ 7 of the 12-week study[241]. In contrast, Javaheri and colleagues employ an

individualized weekly step-count goal determined in partnership with the participant and report 91% adherence to a walking program during radiation therapy.[243] In our study, the prescribed frequency was ≥ 4 weekly sessions for all participants (and not tailored to each individual), which likely affected the reported adherence rates. As such, shared decision-making and goal-setting between the patient and health professional may be ideal to foster good adherence and could be employed in future research.

The time required by PTs to deliver the program was an average of approximately one hour per participant at baseline and 40 minutes at follow-up plus time for documentation. The time allocated to the baseline assessment (excluding introduction to the website) is a part of usual care when referred to rehabilitation following breast cancer surgery in Denmark and therefore not an additional expense for the healthcare system. The follow-up assessment was, however, delivered in addition to usual care to collect study outcomes. While this time commitment may be higher than a standard number of 15 or 30 minutes appointments, one thorough, longer, face-to-face appointment at baseline to guide months of self-managed rehabilitation may be an efficient use of a therapist's time and reduce the burden of BCSs to travel for several appointments. To date, no other study has reported the capacity of delivering a self-managed rehabilitation program which prohibits comparison of our findings to that of others. As such, cost-effectiveness comparisons of self-managed and traditional in-person rehabilitation programs are warranted.

Fewer participants than anticipated used the website. This may be explained by multiple factors. Firstly, the program was offered in addition to usual care, which is quite extensive in Denmark, and may have been sufficient for some participants. Further, more participants used the education pamphlet as this may be more convenient than logging into a website when

performing the rehabilitation exercises routinely. However, among the participants who used the website, the majority reported that the videos helped them perform the rehabilitation exercises more correctly. As such, multiple modes of delivery may be ideal to support BCSs with various preferences for web-based resources[231,234].

Of note, the proportion of BCSs in Part 1 with upper-body issues decreased following the 12-week program. The improvements were expected, as it is well established that rehabilitation exercises are effective in restoring upper-body function after surgery for breast cancer[86]. However, in the absence of a control group, these improvements cannot be attributed to the program. We did not include a control group, as the purpose was to evaluate the feasibility of using the program elements in current practice, which, in Denmark, includes upper-body rehabilitation delivered by PTs for all BCSs. These results show the program is feasible and has the potential to be efficacious, thus suggesting the need for future testing.

Instrumental attitude (i.e., I think the home-based rehabilitation exercises are useful, beneficial, important) most strongly predicted adherence to the self-management program in the current study. While the performance of rehabilitation exercises can be viewed as a rational behavior motivated by the experience of pain or functional limitations, adherence to a rehabilitation program may therefore be predicted by belief in the usefulness and benefits of such behavior[209]. Overall, these results provide preliminary support for the TPB as a framework for developing and evaluating self-managed rehabilitation programs for BCSs. However, given the paucity of research examining theoretical predictors of upper-body rehabilitation, making comparative evaluations are difficult and further research is needed to better understand how to design a program guided by a behaviour change framework.

The main limitation of the study was that only 66% of women referred right after surgery were eligible. An eligibility criterion was access to the internet, as the website was a key component. Based on our findings that the website was not used extensively suggests that the program could be successfully delivered by PTs using only the pamphlet for those without internet access. This may also be effective in older adults by eliminating the barrier of requiring technology. The sample was also homogeneous with regards to location in an urban centre. As a key goal of a self-managed approach is reach outside of the urban centres where access to services is already concentrated, future work is needed to examine this approach in a rural setting. While the recruitment and retention rates were high, completion of the questionnaires demonstrated to be a barrier. Seven to ten percent of eligible patients did not complete the baseline questionnaires and could not be included, and 17% of participants in Part 2 did not complete the follow-up questionnaire and were recorded as dropouts. While this study was carried out in a real-world setting, the importance of such research associated activities may not have been fully communicated to or appreciated by the participants. Therefore, we propose that reach and retention may be higher if this was part of a clinical program that did not require additional time to complete questionnaires.

The BRECOR program has the potential to be successful in improving access to services in a variety of settings as it does not require specific equipment to be carried out and requires only one face-to-face assessment to inform the rehabilitation prescription resulting in no or little out-of-pocket cost for patients. While the program was designed to be offered in addition to usual care in Denmark, it could also be delivered as a stand-alone program in other settings where usual care is less extensive or for patients who cannot access in-person services. Thus, the development and testing of this type of program represents an important step towards reaching

large numbers of BCSs and improving access to high-quality upper-body rehabilitation. As such, future evaluation of the reach, effect, adoption, implementation and maintenance is important when disseminating the BRECOR program into clinical programs across Danish healthcare settings[244].

2.6 Conclusion

Preliminary testing of the BRECOR program suggests it is feasible, acceptable and can assist in restoring upper-body function after treatment for breast cancer. We demonstrated good reach and retention, and participants reported benefit from performing the program. However, effectiveness of the program in reducing the prevalence of upper-body issues will need to be evaluated further.

Chapter 3: Self-measured Arm Circumference in Women with Breast Cancer is Reliable and Valid

3.1 Synopsis

Prospective surveillance by PTs enables early detection and treatment of BCRL. Strategies to increase access to prospective surveillance could reduce the burden of BCRL on patients and the healthcare system. One potential solution is self-managed surveillance that does not require in-person assessment by a specialized PT. This cross-sectional study aimed to develop and test the reliability and validity of a written and video-supported protocol for women with breast cancer to self-measure arm circumference. Participants with (n = 20) and without (n = 21) BCRL completed self-measurement of arm circumference on both arms at home (CIR_{self_home}) and at the lab (CIR_{self_lab}) (intra-rater reliability). The CIR_{self_lab} was subsequently compared to measures performed by a specialized PT (CIR_{ther}) (inter-rater reliability). To test validity, arm volume calculated from the self-measurements (VOL_{self_lab}) was compared to perometry measurements (VOL_{per}). Participants completed a questionnaire to assess attitudes for performing self-managed surveillance for BCRL. Results demonstrate that self-measured arm circumference is reliable and valid. The intra-rater reliability between CIR_{self_home} and CIR_{self_lab} and the inter-rater reliability between CIR_{self_lab} and CIR_{ther} was high to excellent for both arms in both groups (intra-class correlation coefficient (ICC) ≥ 0.86, $p < 0.001$). VOL_{self_lab} correlated strongly with VOL_{per} ($r \geq 0.95$, $p < 0.001$) demonstrating excellent validity. Participants reported strong intention, self-efficacy and positive attitude towards the performance of self-managed surveillance for BCRL, which was not perceived to increase worry about having or getting BCRL. These findings need

to be replicated in a clinical setting to confirm the reliability and acceptability of self-managed surveillance for BCRL among women newly diagnosed with breast cancer.

A version of this chapter has been published as Rafn BS, McNeely ML, Midtgaard J, Camp PG, Campbell KL. Self-measured Arm Circumference in Women with Breast Cancer is Reliable and Valid. *Physical Therapy* 2019; 99(2): 240-253. This work was also presented as a poster presentation at the Combined Sections Meeting of the American Physical Therapy Association held in San Antonio, USA, February 2017.

3.2 Introduction

In 2017, over 247,000 women were diagnosed with breast cancer in the United States and are thus living with or at risk for developing BCRL[245]. The current model of care for identification of BCRL relies on presentation of significant visible swelling that is identified by the patient or a healthcare provider. However, this approach often results in missed or delayed diagnoses of BCRL and a protracted time line for the patient to receive necessary treatment[168,246], which results in more difficult management. Research shows that prospective surveillance for BCRL by a trained PT using sophisticated measurement tools enables early detection and treatment for BCRL and reduces the prevalence of chronic BCRL by 50%[175,247].

A vital component of prospective surveillance is the ability to perform reliable measures to detect BCRL as early as possible, and once BCRL is established, to monitor arm volume and treat exacerbations early[155]. Traditionally BCRL is assessed by serial measures of arm circumference by a trained PT using a tape measure. In addition, other objective and reliable measurement tools for monitoring changes in arm volume and fluid content are integrated into clinical practice with the goal of increasing accuracy, speed and ease of measurement for the PT

and patient, as well as reducing inter-rater error. These approaches, namely water displacement, perometry or bioimpedance analysis, are more commonly available at specialized clinical sites. However, regardless of measurement approach, the main barriers to a therapist-administered surveillance program are access by patients to the services of a trained PT, the ability of the healthcare system to deliver the programming (i.e., clinical time and resources to follow a patient for several years) and the time and effort of the patient to engage in a program[248]. As a result, prospective surveillance is not part of routine care for many patients with breast cancer.

In contrast to therapist-administered surveillance, a self-managed surveillance approach may be effective at improving uptake of prospective surveillance as part of routine care and ultimately reduce the prevalence of morbidity associated with BCRL. A key question to pursuing this approach is if a trained PT is needed in order to obtain accurate and reliable measures of the arm circumference and volume or if it is possible for women to perform the measurements on their own arms. To date, only one study has looked at the correlation of self-measurement to established measurements of circumference and volume in women with breast cancer[249]. Mori et al.[249] recruited 17 women with BCRL who had already undergone intensive decongestive treatment and a PT provided in-person teaching for self-measurement of arm circumference using the traditional tape measure approach. High correlations were reported between self-measurements and measurements performed by a PT ($r = 0.88$ to 0.95) and moderate correlations between volume calculated from circumference measure, obtained by the patient or PT, and water displacement ($r = 0.59$ to 0.68). These findings indicate that women with BCRL who are familiar with arm circumference measures due to extensive interaction with a PT and receipt of ongoing management of BCRL, and who received in-person teaching by a PT can perform self-measured arm circumference in a reliable and valid manner.

To improve the clinical utility of self-managed surveillance for BCRL and reach patients who do not have access to trained PTs, we propose that an approach to self-measurement of arm circumference and volume must: 1) be valid and reliable; 2) be easy to understand, learn and perform; 3) have instructions that do not require in-person teaching, and; 4) be inexpensive, accessible and easy to use and interpret. The purpose of this study was to determine whether women with breast cancer can perform self-measurement of arm circumference in a reliable and valid manner using written and video-supported instructions without in-person teaching by a PT. Specifically, we compared; 1) repeated self-measurements (intra-rater reliability) obtained by women with breast cancer; 2) self-measurements to therapist-measurements (inter-rater reliability), obtained by an experienced PT; and 3) self-measurements to perometer-measurements (criterion validity), the gold standard measure of arm circumference and arm volume. We hypothesized that there would be a high to excellent intra-rater and inter-rater reliability (ICC $\geq$ 0.75), and a moderate to high criterion validity (r $\geq$ 0.5).

3.3 Methods

3.3.1 Design

This study was a cross-sectional reliability and validity study. Ethics approval was provided by the Clinical Research Ethics Board at University of British Columbia (UBC) in Canada (H16-00961) and the trial was registered at ClinicalTrials.gov (Identifier: NCT 02752659).

3.3.2 Participants

Using posters and postings on UBC websites, we recruited a convenient sample of women who had received surgery for breast cancer with axillary or sentinel lymph node dissection,

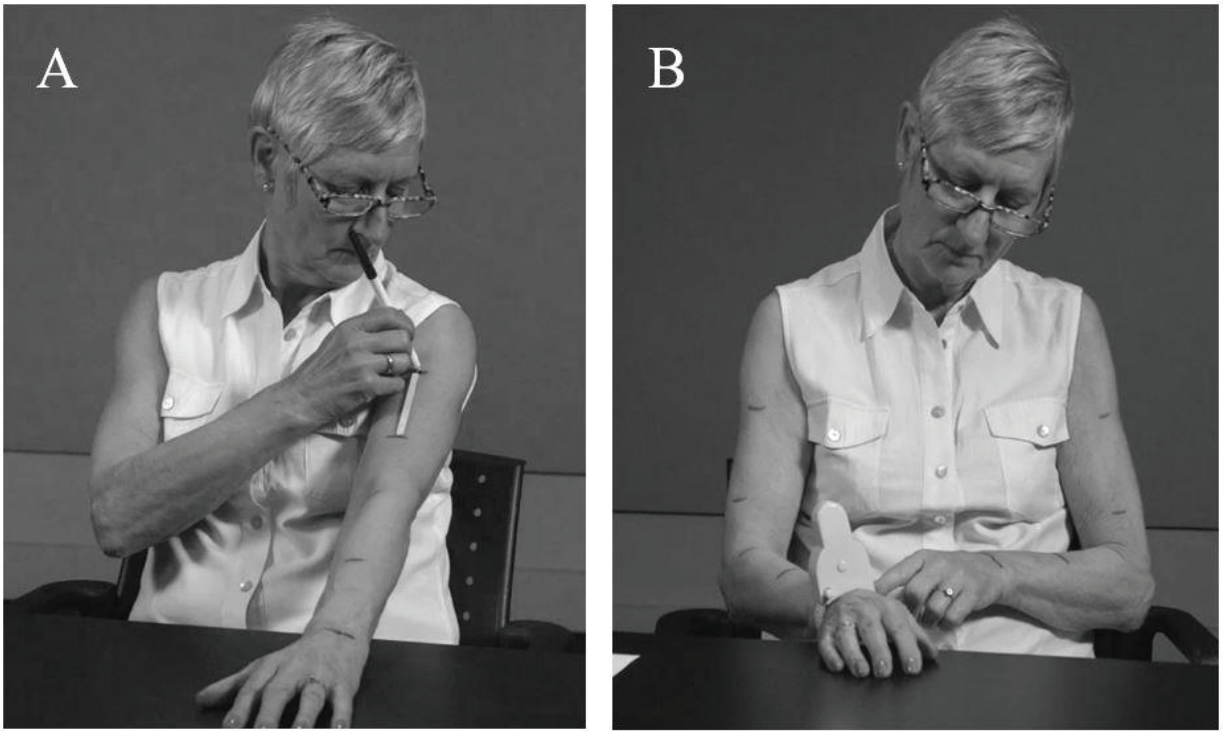
including those who were undergoing chemotherapy or radiation, age 18 or older, who could understand the self-measurement instructions given in English, and who had access and ability to use the internet to view a self-measurement video guide. Participants with and without a clinical diagnosis of BCRL (defined as ≥ 200 ml difference between arms measured by perometry) were eligible. All participants signed an informed consent form prior to beginning the study.

3.3.3 Procedures

The procedure included four steps: 1) self-measurement at home; 2) self-measurement at the UBC laboratory (lab); 3) measurement by trained PT at the lab, and 4) perometer-measurement at the lab. The lab visit took place within 2 days of the home self-measurement. Participants were asked to wear a sleeveless top for both self-measurements. In addition, for both self-measurements participants who wore compression garments were asked to remove these 2 hours before the measurement session in order to control for the effect of compression and to allow the stabilization of their BCRL. All circumference measurements were performed with a tape measure (MyoTape® Body Tape Measure, AccuFitness, Denver, USA), which traditionally is used for measures of body composition and tightens with the push of a button to allow for a hand-free measurement.

Arm circumference measurement protocol: A standardized arm circumference measurement protocol was used for all measures, namely measures performed on both arms at the wrist, and 10, 20, 30, and 40cm proximal to the wrist. Participants were seated with their arm supported on a table and the shoulder in approximately 30 degrees of forward flexion and 45 degrees of elbow flexion. The wrist landmark and additional measurement points at the set distances from the wrist were marked on the skin with a pen (Figure 3.1).

Figure 3. 1 Marking and self-measurement procedure



Home Self-measurement (CIRself_home): This occurred at the participant's home. Participants received a study package by mail, which contained the consent form, the tape measure, written instructions supplemented with photos illustrating each step of the measurement protocol, and a measurement form to record the self-measures (Appendix E). Further, a website link for the video guide with a demonstration on how to perform the measurements was emailed to the participants. Participants were asked to first review the written and video material outlining the measurement process, prior to completing a short quiz on the self-measurement technique (Appendix F). Participants then performed the arm circumference measurements of both arms as per the instructions, recorded the measurements on the provided form and sealed

the form in the provided envelope. The envelope with all study material was returned to the study team at the lab-assessment.

Lab Self-measurement (CIRself_lab): At the UBC lab visit, participants were asked to repeat the self-measurement of arm circumference with support from the video guide and written instructions, unsupervised by a PT.

Therapist-measurement (CIRther): A single specialized PT with experience in arm circumference measures among women with breast cancer performed arm circumference measures for all participants. The PT was blinded to the participants' self-measurement values.

Perometer-measurement: An optoelectronic perometer (Perometer 350S, Pero-system GmbH, Wupertal, Germany) was used to obtain arm circumference and volume measures[250]. Circumference (CIR_{per}) at the same five points (the wrist, and 10, 20, 30, and 40cm proximal to the wrist) and total volume (VOL_{per}) from the wrist to 40cm proximal to the wrist was obtained for each arm. All participants were assessed twice and the average of two consecutive measurements, that were within 1% of each other, was recorded[111,250,251]. If not within 1%, then a third measurement was performed.

3.3.4 Outcome measures

Measured arm circumference: The CIR_{self_home}, CIR_{self_lab}, CIR_{ther} are reported in cm. Standard error of the CIR_{self_home} measurements (SEM) was calculated from the standard deviations and subsequently used to calculate the minimal detectable change. Both were reported in centimeters.

Calculated arm volume: The single truncated cone calculation was used to determine arm volume in ml ($VOL_{self\_home,}$ VOL_{self_lab} and VOL_{ther}) from arm circumference measures CIR_{self_home}, CIR_{self_lab} and CIR_{ther}, respectively. The circumference of the arm at the proximal and distal limits of the segment, together with the length between them, are used to calculate the volume of the segment, by using the following formula: Volume = $\frac{h*(C_1^2+C_1*C_2+C_2^2)}{12*\pi}$, where h = height or length of the cone, C_1= proximal circumference, and , C_2= distal circumference[252].

Measured arm volume: VOL_{per} was reported in ml.

Participant characteristics: Medical and demographic variables were collected in self-report questionnaires at the lab visit. Further, anthropometric measures (height and weight) were collected and used to calculate body mass index (kg/m^2).

Ease of completing self-measurement: The self-reported ease of performing the self-measurements was assessed using a scale from 1 to 10 with higher scores indicating greater ease of performing the measurements.

Motivation to do self-measurement: To assess participants' thoughts about performing self-measures for BCRL, we administered the Thoughts and Beliefs Questionnaire following the completion of all measurements at the lab visit. Two versions of the questionnaire were developed, one that was addressed to participants with BCRL and another to participants without BCRL. This 14-item questionnaire was developed using the Theory of Planned Behavior (TPB)[203], the Health Belief Model (HBM)[253] and the Self-Regulation Model (SRM)[200] (Appendix G).

The first section was developed using TPB and included eight items. Intention to perform self-measures for BCRL was assessed with two items. Instrumental attitude was assessed using two items. Planning and subjective norm were assessed using one item for each scale. Finally, controllability (self-efficacy and perceived behavioral control) was assessed using two items. These items were all scored on a 7-point Likert scale (1 to 7) with higher scores indicating greater level of positive thoughts about the self-measures.

The second section of the questionnaire was developed using HBM and SRM and included five items. Perceived consequence of BCRL was assessed using two items. Perceived risk of BCRL (onset or exacerbation), worry about BCRL, and perceived self-regulation ability were assessed using one item for each scale. The five items in this section were all scored using a 5-point Likert scale (1 to 5) with higher scores indicating greater level of negative thoughts about BCRL. The final item, which was not theoretically grounded, asked whether performing self-measures of arm circumference would increase worry about having/getting BCRL with scores ranking from 1 (not at all) to 5 (very much).

3.3.5 Statistical analysis

Separate analyses were conducted for participant with and without BCRL. Analyses were performed for the affected and unaffected arm among participants with BCRL, and for the dominant and non-dominant for participants without BCRL. The intra-rater and inter-rater reliability were calculated using the intra-class correlation coefficients (ICC) with corresponding 95% confidence intervals for each measurement point (cm) and arm volume (ml). Pearson's correlation (r) and the level of agreement between VOL_{self_lab} and VOL_{per} were calculated to determine criterion validity. The mean of these differences indicated bias (%) were calculated for

VOL_{self_lab} and VOL_{per} and illustrated using Bland-Altman plots. The self-reported ease of performing the measurements at home and at the lab was compared using paired t-tests.

The motivational data based on TPB was categorized in three levels; "strong" for a mean score of ≥ 6, "moderate" for a mean score between 3 and 5, and "weak" for a mean score of ≤ 2. Similarly, the motivational data based on HBM and SRM was categorized in three levels; "much/very much" for a score of ≥ 4, "neutral" for a score 3, and "not at all/somewhat" for a score of ≤ 2.

3.3.6 Sample size

Based on our hypothesis of detecting a high to excellent agreement of ICC ≥ 0.75 between CIR_{self_home} and CIR_{self_lab} (intra-rater reliability) as well as between CIR_{self_lab} and CIR_{ther} (inter-rater reliability), a sample size of 11 subjects per group was needed (alpha = 0.05, 80% power). In order to detect a moderate correlation of r ≥ 0.50 for criterion validity (VOL_{self_lab} and VOL_{per}), a sample size of 20 subjects per group was needed (alpha = 0.05, 80% power).

3.4 Results

Forty-one participants were included, specifically 20 participants with and 21 without BCRL, with a mean age of 62 (7.5) years and 59 (10.6) years, respectively. More participants with BCRL had undergone axillary lymph node dissection and had higher number of lymph nodes removed than participants without BCRL (Table 3.1). All participants completed the study with no missing data across groups.

Table 3. 1 Participant characteristics

	Participants with BCRL n = 20	Participants without BCRL n = 21	p-value
Age, years (SD)	62.00 (7.46)	58.48 (10.56)	0.24
BMI, kg/m^2 (SD)	27.97 (4.06)	26.25 (5.62)	0.27
Ethnicity, n (%)			
Caucasian	17 (85.0)	19 (90.5)	0.59
Asian	3 (15.0)	2 (9.5)	
Marital status, n (%)			
Married/common law	14 (70.0)	13 (61.9)	
Separated/divorced	2 (10.0)	3 (14.3)	0.75
Widowed	2 (10.0)	1 (4.8)	
Single	2 (10.0)	4 (19.0)	
Education, n (%)			
High school	2 (10.0)	0 (0)	0.26
University/college	13 (65.0)	13 (61.9)	
Graduate school	5 (25.0)	8 (38.1)	
Family income, n (%)			
<$40,000/year	1 (5.0)	2 (9.5)	
$40,000-$80,000/year	9 (45.0)	7 (33.3)	0.21
$80,000-$100,000/year	10 (50.0)	11 (52.4)	
Not reported	0 (0)	1 (4.8)	
Breast cancer stage, n (%)			
I	0 (0)	6 (28.6)	
II	7 (35.0)	10 (47.6)	0.02
III	12 (60.0)	5 (23.8)	
IV	1 (5.0)	0 (0)	
Surgery, n (%)			
Mastectomy	14 (70.0)	11 (52.4)	0.25
Lumpectomy	6 (30.0)	10 (47.6)	
Post-surgical complications, n (%)			
Infection	3 (15.0)	3 (14.3)	0.95
Drainage issues	5 (25.0)	3 (14.3)	0.39
Seroma	3 (15.0)	2 (9.5)	0.59
Hematoma	0 (0)	0 (0)	-
Lymph node dissection, n (%)			
Axillary	19 (95.0)	6 (28.6)	
Sentinel	1 (5.0)	14 (66.7)	<0.001
Not reported	0 (0)	1 (4.8)	
Number of nodes removed			
mean (SD)	13.30 (4.60)	6.55 (7.01)	<0.001
Adjuvant treatment, n (%)			
Chemotherapy	18 (90.0)	18 (85.7)	0.68
Radiation	17 (85.0)	17 (80.9)	0.73
Breast	16 (80.0)	16 (76.2)	0.77
Axilla	11 (55.0)	8 (38.1)	0.28
Supra-clavicular	5 (25.0)	3 (14.3)	0.39
Time since surgery			
years (SD)	7.11 (5.97)	4.09 (4.55)	0.17
Time since BCRL onset			
years (SD)	5.09 (5.20)	N.A.	-

Legend: BCRL: breast cancer-related lymphedema

Among participants without BCRL, there was high to excellent intra-rater reliability between CIR_{self_home} and CIR_{self_lab} for all points of measure and volume (ICC ≥ 0.86, 95% CI 0.64; 0.94, $p < 0.001$) (Table 3.2). Among participants with BCRL, there was excellent intra-rater reliability between CIR_{self_home} and CIR_{self_lab} for all points of measure and volume (ICC ≥ 0.93, 95% CI 0.83; 0.97, $p < 0.001$). Similarly, the inter-rater reliability was high to excellent between CIR_{self_lab} and CIR_{ther} for all points of measure and volume among participants without BCRL (ICC ≥ 0.88, 95% CI 0.67; 0.96, $p < 0.001$), and excellent among participants with BCRL (ICC ≥ 0.91, 95% CI 0.41; 0.98, $p < 0.001$) (Table 3.2). The minimal detectable change ranged from 0.35cm to 1.56cm for participants without BCRL and from 0.34cm to 1.16cm among participants with BCRL (Table 3.3). Participants with and without BCRL reported ease of performing the self-measurements both at home and at the lab (with BCRL: CIR_{self_home}: 7.4 (2.2) and CIR_{self_lab}: 8.0 (1.9), $p = 0.05$) and (without BCRL: CIR_{self_home}: 6.6 (2.6) and CIR_{self_lab}: 7.3 (2.2), $p = 0.04$)

Table 3. 2 Reliability of self-measured arm circumference

	Participants with BCRL n = 20						Participants without BCRL n = 21					
	Affected arm			Unaffected arm			Dominant arm			Non-dominant arm		
Point of measure	ICC	95% CI	p-value	ICC	95% CI	p-value	ICC	95% CI	p-value	ICC	95% CI	p-value
Wrist												
Intra-rater	0.96	0.91;0.99	<0.001	0.93	0.83;0.97	<0.001	0.96	0.89;0.98	<0.001	0.95	0.88;0.98	<0.001
Inter-rater	0.95	0.70;0.99	<0.001	0.91	0.42;0.98	<0.001	0.91	0.76;0.96	<0.001	0.88	0.67;0.96	<0.001
10cm												
Intra-rater	0.98	0.94;0.99	<0.001	0.96	0.89;0.98	<0.001	0.91	0.77;0.96	<0.001	0.86	0.64;0.94	<0.001
Inter-rater	0.99	0.97;1.00	<0.001	0.97	0.92;0.99	<0.001	0.97	0.93;0.99	<0.001	0.97	0.93;0.99	<0.001
20cm												
Intra-rater	0.99	0.96;0.99	<0.001	0.98	0.96;0.99	<0.001	0.97	0.91;0.99	<0.001	0.97	0.93;0.99	<0.001
Inter-rater	0.99	0.84;1.00	<0.001	0.98	0.94;0.99	<0.001	0.97	0.91;0.99	<0.001	0.98	0.93;0.99	<0.001
30cm												
Intra-rater	0.93	0.83;0.97	<0.001	0.98	0.95;0.99	<0.001	0.98	0.95;0.99	<0.001	0.96	0.91;0.99	<0.001
Inter-rater	0.99	0.97;1.00	<0.001	0.99	0.96;1.00	<0.001	0.99	0.93;1.00	<0.001	0.98	0.96;0.99	<0.001
40cm												
Intra-rater	0.99	0.98;1.00	<0.001	0.98	0.95;0.99	<0.001	0.99	0.97;1.00	<0.001	0.99	0.97;0.99	<0.001
Inter-rater	1.00	1.00;1.00	<0.001	1.00	1.00;1.00	<0.001	0.99	0.98;1.00	<0.001	1.00	0.99;1.00	<0.001
Volume												
Intra-rater	0.99	0.98;1.00	<0.001	0.99	0.98;1.00	<0.001	0.98	0.96;0.99	<0.001	0.98	0.96;0.99	<0.001
Inter-rater	1.00	1.00;1.00	<0.001	1.00	0.99;1.00	<0.001	0.99	0.98;1.00	<0.001	0.99	0.97;1.00	<0.001

Legend: BCRL: breast cancer-related lymphedema. Intra-rater reliability compared CIR_{self_home} with $CIR_{self\_lab,}$ and $VOL_{self_home}$with VOL_{self_lab}. Inter-rater reliability compared CIR_{self_lab} with CIR_{ther} and VOL_{self_lab} with VOL_{ther}.
CIR_{self_home}: self-measured circumference at home. CIR_{self_lab}: self-measured circumference at laboratory, CIR_{ther}: therapist-measured circumference.
VOL_{self_home}: volume calculated from the self-measures performed at home. VOL_{self_lab}: volume calculated from the self-measures performed at laboratory

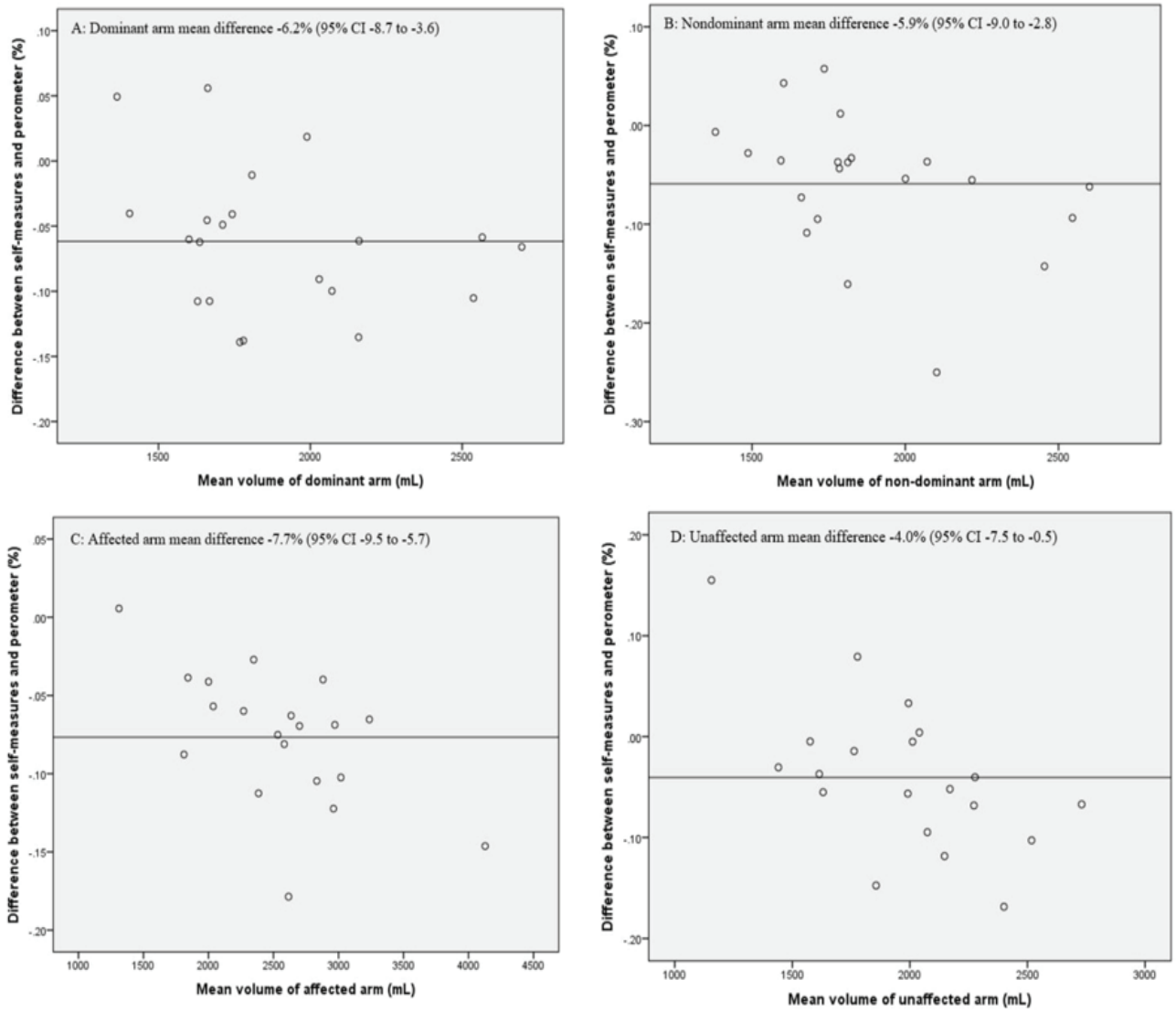
Table 3. 3 Standard error of the measurement and minimal detectable change for self-measured arm circumference at home

	Participants with BCRL n = 20						Participants without BCRL n = 21					
	Affected arm			Unaffected arm			Dominant arm			Non-dominant arm		
Point of measure	SD	SEM	MDC	SD	SEM	MDC	SD	SEM	MDC	SD	SEM	MDC
Wrist	1.20	0.20	0.57	0.97	0.26	0.73	0.73	0.15	0.42	0.58	0.12	0.35
10cm	2.95	0.42	1.16	1.55	0.34	0.93	1.56	0.47	1.30	1.50	0.56	1.56
20cm	3.22	0.37	1.02	1.73	0.23	0.64	1.60	0.29	0.80	1.44	0.25	0.68
30cm	3.59	1.03	0.35	2.77	0.35	0.97	2.52	0.35	0.96	2.60	0.50	1.39
40cm	3.94	0.12	0.34	3.25	0.18	0.49	4.30	0.45	1.25	4.52	0.53	1.48

Legend: BCRL: breast cancer-related lymphedema, CIR_{self_home}: self-measured circumference at home, MDC: Minimal detectable change in cm with 95% confidence, SEM: standard error of the measurement in cm, SD: standard deviation.

There was an almost perfect correlation between VOL_{self_lab} and VOL_{per} among participants with BCRL ($r = 0.98$, $p < 0.001$) and without BCRL ($r = 0.95$, $p < 0.001$). For participants without BCRL, the difference (%) between VOL_{self_lab} and VOL_{per} was -6.2% (95% CI -8.7; -3.6) and -5.9% (95% CI -9.0; -2.8) for the dominant and non-dominant arm, respectively (Figure 3.2A and B). For participants with BCRL, the difference (%) between VOL_{self_lab} and VOL_{per} was -4.0% (95% CI -9.7; -5.7) and -7.7% (95% CI -7.5; -0.5) for the unaffected and affected arm, respectively (Figure 3.2C and D).

Figure 3. 2 Bland-Altman plot of the mean difference between arm volumes from perometer and calculated from self-measured arm circumference



Participants reported strong intention to perform the self-measurements at home, positive attitude and strong self-efficacy towards self-managed surveillance for BCRL (Table 3.4).

Further, self-managed surveillance for BCRL was not perceived to increase worry about developing or having BCRL by most participants.

Table 3. 4 Motivation to do self-measurement for breast cancer-related lymphedema

	Participants with BCRL n = 20	**Participants without BCRL n = 21**	**p-value**
	n (%)	n (%)	
Intention (I intend to do the self-measurements at home every three months)			
Strong	19 (95.0)	14 (66.7)	
Moderate	1 (5.0)	5 (23.8)	0.14
Weak	0 (0)	2 (9.5)	
Instrumental Attitude (I think that self-measurement would be helpful/important)			
Positive	18 (90.0)	14 (66.7)	
Neutral	2 (10.0)	6 (28.6)	0.28
Negative	0 (0)	1 (4.8)	
Subjective Norm (If I do self-measurement people who are important to me would be supportive)			
Strong	19 (95.0)	17 (81.0)	
Moderate	1 (5.0)	4 (19.0)	0.17
Weak	0 (0)	0 (0)	
Controllability (I have control over whether I do self-measurements every three months)			
Strong	19 (95.0)	20 (95.2)	
Moderate	1 (5.0)	1 (4.8)	0.97
Weak	0 (0)	0 (0)	
Self-efficacy (I am confident that I can do self-measurements every three months)			
Strong	19 (95.0)	17 (81.0)	
Moderate	1 (5.0)	4 (19.0)	0.17
Weak	0 (0)	0 (0)	
Planning (I have a plan for how I will do the self-measurements every three months)			
Strong	18 (90.0)	11 (52.4)	
Moderate	2 (10.0)	5 (23.8)	0.02
Weak	0 (0)	5 (23.8)	
BCRL is a serious condition			
Much/very much	19 (95.0)	21 (100)	0.30
Neutral	1 (5.0)	0 (0)	
Not at all/somewhat	0 (0)	0 (0)	
Having/getting BCRL interferes with my life			
Much/very much	13 (65.0)	21 (100)	
Neutral	4 (20.0)	0 (0)	0.01
Not at all/somewhat	3 (15.0)	0 (0)	
Perceived risk of BCRL onset/exacerbation			
Much/very much	10 (50.0)	6 (28.6)	
Neutral	7 (35.0)	7 (33.3)	0.20
Not at all/somewhat	3 (15.0)	8 (38.1)	
Self-regulation ability			
Much/very much	12 (60.0)	13 (61.9)	0.58
Neutral	6 (30.0)	4 (19.0)	
Not at all/somewhat	2 (10.0)	4 (19.0)	
Worry about getting/having BCRL			
Much/very much	13 (65.0)	11 (52.4)	0.39

	Participants with BCRL n = 20	Participants without BCRL n = 21	p-value
Neutral	4 (20.0)	3 (14.3)	
Not at all/somewhat	3 (15.0)	7 (33.3)	
Self-measurement would increase my worry about having/getting BCRL			
Much/very much	2 (10.0)	3 (14.3)	
Neutral	5 (25.0)	6 (28.6)	0.86
Not at all/somewhat	13 (65.0)	12 (57.1)	

Legend: BCRL: breast cancer-related lymphedema

3.5 Discussion

The developed materials and approach to self-measurement of arm circumference demonstrated excellent reliability among women with and without BCRL. Furthermore, we demonstrated an almost perfect correlation between arm volume calculated from self-measured arm circumference and that obtained from the perometer indicating high criterion validity. However, in line with previous research[254], the volume obtained from circumference measurements was 4 to 8% lower than that obtained from the perometer and the two tools should therefore not be used interchangeably in a clinical setting. Lastly, we demonstrated small measurement errors allowing the detection of subtle changes in arm circumference using measurements obtained by women with breast cancer at home without in-person teaching by a PT.

We employed a simple protocol of five measurement points in accordance with previous research[255]. Using this protocol, subtle increases in circumference at the 2^{nd,} 3rd and 4th measurement point (located at 10cm, 20cm and 30cm proximal to the wrist) have been demonstrated to predict the onset of subclinical BCRL[256]. The findings by Stout and colleagues[256] suggest that changes at the earliest onset of BCRL would likely occur in the superficial tissue, primarily the forearm and distal upper arm, potentially due early

microlymphatic changes in the deep muscle bulk of the forearm that creates a longer route for lymph drainage in this region[257]. While optimal monitoring for BCRL should be comprehensive with multiple measurement points, Stout et al. suggest that the segments 10-20cm and 20-30cm may have the most clinical utility because of their ability to explain a large amount of the variance in volume and should be explicitly targeted and monitored for meaningful change[256]. This highlights the importance to include these three measurements points (10cm, 20cm and 30cm proximal to the wrist) when monitoring for BCRL and lends support for the protocol used in the current study.

To further optimize the ability for early detection of BCRL, recently prediction models (nomograms) have been developed to predict who will develop BCRL based on patient characteristics (age, body mass index), extent of cancer therapy (radiation therapy, axillary surgery, chemotherapy infusions) and post-surgery complications (seroma, swelling)[258,259]. However, to date, these models have been demonstrated to be inaccurate in identifying people who develop BCRL in a clinical setting[259]. Frequent monitoring of arm circumference and volume among women at risk for BCRL therefore continues to be the most effective method to enable early detection and intervention to reduce the incidence of clinical BCRL[260].

The ability of women with breast cancer to obtain accurate, reliable and valid measures of arm circumference by self-measurement, without in-person teaching by a PT, is highly relevant due to the growing number of breast cancer diagnoses. New modes of delivering prospective surveillance for BCRL are needed to extend the reach of and promote equal access to surveillance programs to ensure early detection of new onset or exacerbation. Previously, Lette and colleagues[261] developed a device for home-measurement of arm volume using the water displacement method and demonstrated high accuracy compared to a traditional, clinic-based

water displacement device. However, for people who do not have the skills or energy to build their own water displacement device, circumference measurements using an off the shelf tape measure is a simple and efficient alternative option for home measurement.

We demonstrated strong self-efficacy and positive attitudes towards self-measurement among the participants. Independence in the ability to perform objective self-measurement of physiological conditions is suggested to be necessary to promote self-regulation or self-care of BCRL[262]. Further, the importance of positive beliefs regarding the controllability of BCRL through early detection and management has been demonstrated to be associated with adherence to risk-management recommendations[263]. In line with this, participants in the current study found the approach easy to learn and perform, and participants with BCRL reported strong intention to use this new approach as a part of their self-care strategies to manage the BCRL. A potential concern with recommending self-measurement is the potential for increased anxiety related to developing or having BCRL. However, while participants in the study considered BCRL to be a serious condition, self-measurement was not associated with increased anxiety about developing or having BCRL by most participants. These results are in line with a 2017 Cochrane review of 22 randomized trials and four quasi-randomized trials that demonstrated benefit of home-based self-management programs for women with breast cancer in reducing anxiety[264]. Future prospective trials are warranted to test if providing the resources and knowledge on self-managed surveillance for BCRL supports self-efficacy, reduces anxiety related to the condition and supports long-term sustainability of self-surveillance.

Strengths of our study include the development of written instructions and a video guide intended for distance-based delivery of resources to promote self-measurements at home without teaching or supervision by a PT. The goal was to evaluate the reliability and validity of self-

measurement as part of an overall self-surveillance strategy for early detection of BCRL. An inexpensive tape measure was used that is easily available for online purchase, along with an inexpensive measurement stick, to limit barriers around cost of equipment. We therefore believe that this approach has high clinical utility to promote independence in detecting changes in arm size by using low-tech measurement tools, with easily interpreted outcomes that is supported by educational resources that can be accessed at home. This approach showed excellent reliability for women to obtain consistent measurements across several days and that measurements taken by the participant were consistent with those obtained by an experienced PT. In addition, validity was evaluated using the perometer, one of the gold standard measurement tools[155]. In terms of limitations, all participants in the study had access to the internet. Moreover, the performance of the written material alone was not tested. While our findings support the potential of self-managed surveillance for BCRL, it is imperative that this self-measurement approach is tested in a clinical setting with women who are newly diagnosed for breast cancer to evaluate the reliability and validity within the context of a clinical program. In addition, the effectiveness, cost-effectiveness and long-term feasibility of self-managed prospective surveillance for BCRL compared to therapist-led prospective surveillance for BCRL must be formally tested.

3.6 Clinical relevance

Physical therapists play a key role in advocating for the provision of prospective surveillance and access to physical therapy treatment, to address common side effects of cancer treatment, such as BCRL[166]. For women at risk of BCRL, self-managed surveillance has the potential to provide cost-efficient early detection of onset of BCRL, which can lead to earlier treatment and better prognosis[168]. Women with BCRL are at risk of exacerbations[66] and this self-

measurement approach also offers an opportunity to independently detect exacerbations due to aggravating factors (i.e. summer heat, air travel, skin cuts) and monitor the effectiveness of their self-management strategies and compression garments, along with proactively seeking out treatment by a PT as needed. This self-measurement approach may thereby provide PTs and other clinicians, such as breast surgeons, oncologists or oncology nurses, the opportunity to provide reliable and valid method for surveillance for BCRL that can reach a greater number of breast cancer survivors, including those living in rural or remote areas, who would otherwise not receive surveillance for BCRL.

3.7 Conclusion

Video and written material with instructions on how to perform self-measurement of arm circumference results is reliable and valid measurements and promotes confidence among women with and without BCRL in performing self-measurement. This approach therefore has the potential to have a substantial impact on improving the reach of prospective surveillance programs to detect BCRL early and facilitated more timely treatment by a PT.

Chapter 4: Self-managed Surveillance for Breast Cancer-Related Upper-Body Issues: A Feasibility and Reliability study

4.1 Synopsis

Early identification of breast cancer-related upper-body issues is important to enable timely physical therapy treatment. This prospective single-site, single-group study aimed to evaluate the feasibility and reliability of women performing self-managed prospective surveillance for upper-body issues as part of a hospital-based surgical program. Pre-surgery arm circumference measurements were completed at home and at the hospital by participants and by a PT. Instruction in self-measurement was provided using a video guide. Post-surgery, all circumference measurements were repeated along with self-assessment and therapist-assessment for shoulder flexion and abduction active ROM. Feasibility was determined by recruitment and retention rates, and participant-reported ease of performing self-measurements (1 "very difficult" to 10 "very easy"). Thirty-three women aged 53.4 (11.4) years participated with recruitment and retention rates of 79% and 94%. Participant-reported ease of measurement was 8.2 ± 2.2 at pre-surgery and 8.0 ± 1.9 at post-surgery. The intra-rater and inter-rater reliability were excellent at pre-surgery (ICC ≥ 0.94, 95% CI 0.87; 0.97) and at post-surgery (ICC ≥ 0.91, 95% CI 0.76; 0.96). Agreement was good between self-assessed and therapist-assessed active shoulder flexion ($\kappa = 0.79$) and abduction ($\kappa = 0.71$). Further testing is needed using a prospective design with longer follow-up to determine if self-managed surveillance and timely treatment can hinder the development of chronic breast cancer-related upper-body issues.

A version of this chapter is submitted for publication and is currently under review as Rafn BS, Singh CA, Midtgaard J, Camp PG, McNeely ML, Campbell KL. Self-managed Surveillance for Breast Cancer-related Upper-body Issues: A Feasibility and Reliability Study. This work was also presented as a poster presentation at the European Survivorship and Rehabilitation Symposium held in Copenhagen, Denmark, September 2018.

4.2 Introduction

In 2018, more than 3.1 million breast cancer survivors are alive in the United States and thus live with, or are at risk for developing breast-cancer related upper-body issues[265]. These issues include upper-body pain and tightness, limitations in shoulder ROM, impaired muscular strength and BCRL. Most patients experience these issues during and/or after treatment[266] and many develop chronic issues with long-term implications on activities and participation[267], and quality of life[49].

Early identification of breast cancer-related upper-body issues is important to enable timely physical therapy treatment which improves health outcomes[179] and cost-effectiveness of care[266]. Research shows that prospective surveillance for breast-cancer related upper-body issues by a trained PT enables early detection and treatment, and reduces the complexity of the issues[179] and prevalence of chronic BCRL[175,247]. However, the main barriers to a surveillance program are access by patients to the services of a trained PT, the ability of the healthcare system to deliver the programming (i.e., clinical time and resources to follow a patient for several years) and the time and effort of the patient to engage in a program[248]. In addition, traditionally an in-person physical examination of shoulder ROM or arm circumference by a trained PT is required as part of a surveillance program, which exacerbates all of these barriers. As a result, prospective

surveillance for upper-body issues is not part of routine care for many patients with breast cancer.

To support patients and clinicians in monitoring the development of breast-cancer related upper-body issues, ideally patients at risk would be trained to do measurements and monitor the development of issues themselves in a simple way. Self-managed surveillance for upper-body issues has a number of potential advantages including: 1) the tester is consistent throughout time (namely the patient him/herself) and can use the same measurement procedure consistently (as opposed to different healthcare professionals who use different measurement tools and procedures); 2) the timing of measurement is more flexible than structured PT visits on a set schedule and measurement can be performed when the patient feels it is needed; 3) the patient is independent, and thus supports patient self-determination; 4) the burden on the healthcare system for surveillance assessments is reduced (i.e., clinician time, availability, and space); and 5) the burden on the patient (i.e., cost and travel time) to see a PT in a public or private setting is reduced.

We recently demonstrated that women with breast cancer (both with and without BCRL) can perform measures of arm circumference in a reliable and valid manner on themselves[268]. Using an inexpensive tape measure and a video guide, women who had completed treatment for breast cancer were able to perform reliable measurements at home and at a laboratory setting without in-person teaching or supervision by a PT. While providing preliminary support for the clinical utility of a self-managed approach for prospective surveillance for BCRL, these findings need to be replicated in a clinical setting with women who are scheduled for breast cancer surgery to determine if the results are reproducible. The program also needs to be expanded to test self-managed surveillance for other upper-body issues such as limitations in shoulder ROM. Such

structural limitations often directly impact activities and participation[269] and are thus important to detect and manage early to avoid the development of chronic limitations. Key factors to determine the utility of self-managed surveillance for upper-body issues include assessing the feasibility of integrating this approach into a clinical care pathway for women who are scheduled to receive surgery for breast cancer.

The purpose of this study was to determine the feasibility and reliability of participant self-managed surveillance of upper-body issues. Specifically, we compared: 1) repeated participant self-measurements of arm circumference (intra-rater reliability), carried out by women with breast cancer at pre-surgery and post-surgery; 2) participant self-measurements of arm circumference to therapist-measurements (inter-rater reliability), carried out by an experienced PT; and 3) participant self-assessment of shoulder ROM to therapist-assessment (agreement). Feasibility was determined by: 1) recruitment and retention rates; and 2) participant-reported ease of performing self-measurements for arm circumference.

4.3 Methods

4.3.1 Design

This study was a prospective single-site, single-group feasibility and reliability study. Ethics approval was provided by The Clinical Research Ethics Board at the University of British Columbia (UBC) (H17-01992).

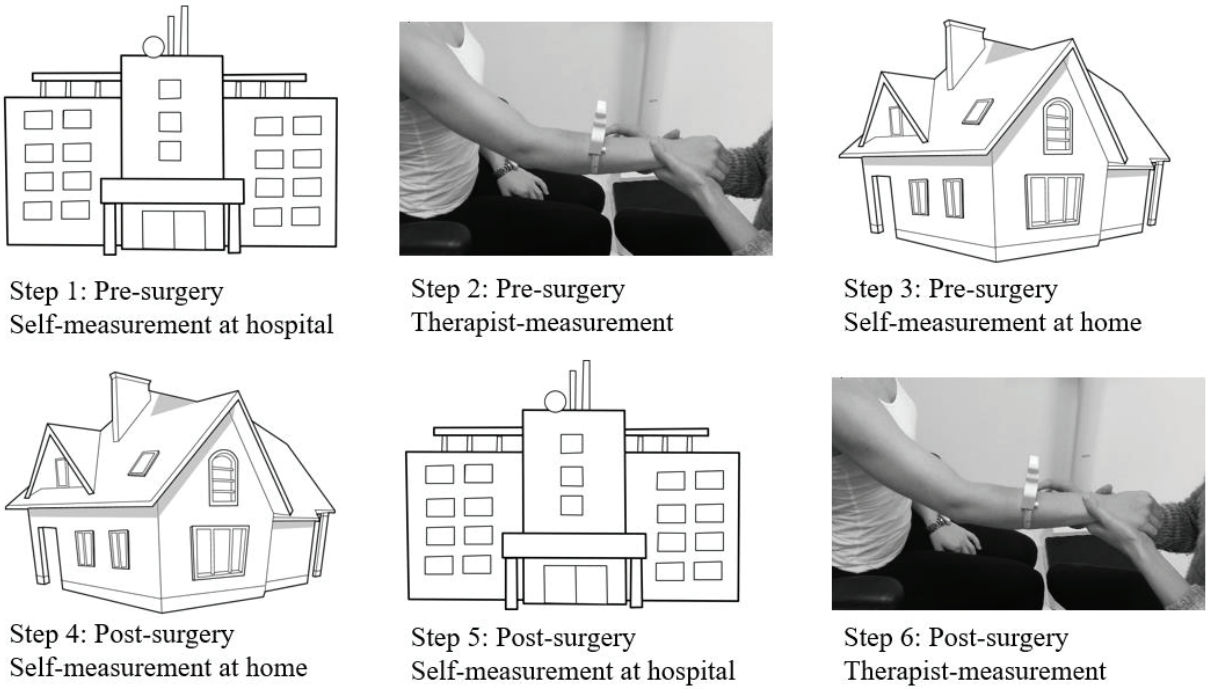
4.3.2 Participants

Patients who met the following criteria were invited to participate: women scheduled to receive any type of surgery for breast cancer at Surrey Memorial Hospital (SMH); age 18 or older; who understand the self-measurement instructions given in English or Punjabi; who have access and ability to use the internet to view the self-measurement video guide. All participants signed an informed consent form prior to beginning the study.

4.3.3 Procedure

The procedure included three steps: 1) participant self-measurement at the hospital; 2) participant self-measurement at home; 3) measurement by a trained PT at the hospital. These three steps were completed at pre-surgery and once at early post-surgery (the session was scheduled between one and three months post-surgery) (Figure 4.1). The hospital measurements were performed during: 1) the patient education class at pre-surgery; and 2) the individual follow-up appointment with a PT at post-surgery. Both hospital appointments are part of usual care at SMH. Participants wore a sleeveless top for all measurements and were unsupervised by a PT for all self-measurements. The home measurements took place within 2 days of the hospital measurements.

Figure 4. 1 Procedure for arm circumference measurement at pre-surgery and post-surgery



4.3.4 Self-measurement resources

Prior to attending the pre-surgery education class, participants received a video guide via email along with print information that demonstrated the marking and circumference measurement procedure. The resources were developed in English and Punjabi to match the ethnic population of Surrey in British Columbia, Canada, where the study took place.

4.3.5 Arm circumference measurement

A standardized arm circumference measurement protocol was used for all measures. The measures were performed on both arms at the wrist, and 10, 20, 30, and 40cm proximal to the wrist[268]. All circumference measurements were performed with a tape measure (Body Fat

Measuring Tool, Richarts, Hong Kong), which tightens with the push of a button to allow for a hands-free measurement.

Hospital Self-measurement ($CIR_{self\_hospital}$): Participants completed self-measurement for arm circumference at: 1) their pre-surgery visit, and 2) the post-surgery follow-up appointment. To support the self-measurements, participants watched the video guide at the hospital and were provided with print instructions with photos (Appendix E), a tape measure, and a measurement stick.

Therapist-measurement ($CIR_{therapist}$): A PT with several years of experience in arm circumference measures for patients with breast cancer performed circumference measures on participants. Measurements were performed: 1) during the patient education class at pre-surgery; and 2) at the follow-up appointment at post-surgery. The PT was blinded to the values obtained by self-measurement.

Home Self-measurement (CIR_{self_home}): Participants performed the self-measurements at home within two days of their visit to the hospital at: 1) pre-surgery; and 2) post-surgery with support from the video guide and print instructions.

4.3.6 Shoulder range of motion assessment

During the post-surgery follow-up appointment, participants assessed their own active shoulder ROM. While standing in front of a mirror, participants performed active flexion and abduction and reported if the ROM on the side of surgery was reduced compared to the non-surgical side (yes/no) and whether the movement was painful (yes/no) (Appendix H). Only participants with unilateral surgery performed this assessment. Following the self-assessment, a

PT performed same assessment and recorded if the movements on the surgical side were reduced compared to the non-surgical side (yes/no) (Appendix I). If yes, the PT assessed the active ROM using a goniometer in supported supine position and recorded the degrees of movement.

4.3.7 Outcome measures

Feasibility outcomes: Feasibility was determined by recruitment rate, retention rate, and participant-reported ease of performing self-measurement. Recruitment rate was calculated as the proportion of included participants relative to the number of eligible, invited patients. The retention rate was calculated as the proportion of enrolled participants who performed the self-measurements at post-surgery either at home or at the post-surgery visit (or both).

The self-reported ease of performing the self-measurements at home was assessed at pre-surgery and post-surgery using a single question: "Were the self-measures difficult to perform?" with a scale from 1 to 10 with higher scores indicating greater ease of performing the measurements.

Participant characteristics: Demographic information and medical variables including post-surgical complications and planned adjuvant treatment were collected in self-report questionnaires at the pre-surgery and post-surgery hospital visit.

Measured arm circumference: The CIR_{self_home}, $CIR_{self\_hospital}$, $CIR_{therapist}$ are reported in centimeters (cm). Standard error of the CIR_{self_home} measurements (SEM) was calculated from the standard deviations and subsequently used to calculate the minimal detectable change (MDC) with 95% confidence (95%MDC).

Calculated arm volume: The single truncated cone calculation was used to determine arm volume in milliliters (ml) (VOL_{self_home}, $VOL_{self\_hospital}$ and $VOL_{therapist}$) from arm circumference measures (CIR_{self_home}, $CIR_{self\_hospital}$ and $CIR_{therapist}$, respectively). The circumference of the arm at the proximal and distal limits of the segment, together with the length between them, was used to calculate the volume of the segment, by using the following formula: Volume = $\frac{h*(C_1^2+C_1*C_2+C_2^2)}{12*\pi}$, where h = height or length of the cone, C_1 = proximal circumference, and , C_2 = distal circumference[252]. SEM (ml) and 95%MDC were calculated from the volume obtained from the CIR_{self_home} measurements.

Shoulder range of motion: The agreement between the self-assessed and therapist-assessed shoulder ROM was calculated for flexion and abduction. The limitations (degrees) in shoulder ROM measured by the PT were reported.

4.3.8 Statistical analysis

Descriptive statistics are reported as number and proportion, mean and standard deviation, or median and quartiles. Analyses were performed for the dominant and non-dominant limb. The intra-rater and inter-rater reliability at pre-surgery and post-surgery was calculated using the intra-class correlation coefficients (ICC) with corresponding 95% confidence intervals for each measurement point (cm) and arm volume (ml). For agreement in shoulder ROM, Cohen's kappa (κ) was used. $\kappa > 0.60$ is considered good/substantial, while $\kappa > 0.80$ is considered as almost perfect agreement[270].

The self-reported ease of performing the measurements at pre-surgery and post-surgery was compared using paired t-tests. The analyses were two-sided and carried out using the IBM SPSS™ version 25.0.

4.4 Results

A total of forty-two patients scheduled for surgery for breast cancer were eligible and invited to participate. Thirty-three consented to participate (recruitment rate 79%) and thirty-one participants completed the study (retention rate 94%). The follow-up appointment occurred at a mean of 7.3 (2.4) weeks post-surgery. Participants had a mean age of 53.4 (11.4) years and a wide range in education level and family income. Most participants had mastectomy surgery and sentinel lymph node dissection (Table 4.1). In total, 960 circumference measurements were analyzed.

Table 4. 1 Participant characteristics

	n = 33
Age, years (SD)	53.4 (11.4)
Ethnicity, n (%)	
White	25 (76)
Asian	5 (16)
Other	1 (3)
Marital status, n (%)	
Married/common law	24 (73)
Separated/divorced	6 (19)
Widowed	3 (10)
Education, n (%)	
Some High School	4 (12)
Completed High School	6 (18)
Some University/College	8 (26)
Completed University/College	12 (39)
Some Graduate School	1 (3)
Completed Graduate School	2 (6)
Family income, n (%)	
<$20,000/year	3 (9)
$20-39,999/year	4 (13)
$40-59,999/year	8 (26)
$60-79,999/year	3 (10)

	n = 33
$80-99,999/year	6 (19)
>$100,000/year	6 (19)
Not reported	3 (9)
Family history of breast cancer, n (%)	11 (35)
Family history of BCRL, n (%)	5 (16)
Breast cancer stage, n (%)	
I	17 (55)
II	8 (24)
III	6 (19)
Not reported	2 (6)
Surgery, n (%)	
Mastectomy	26 (79)
Lumpectomy	6 (19)
Not reported	1 (3)
Reconstruction surgery (immediate or delayed), n (%)	23 (70)
Post-surgical complications, n (%)	
Infection	4 (13)
Drainage issues	2 (6)
Seroma	2 (6)
Hematoma	2 (6)
Lymph node dissection, n (%)	
Axillary	13 (39)
Sentinel	19 (58)
Not reported	1 (3)
Number of nodes removed, mean (SD)	7.6 (10.4)
Min-Max	1-58
Number of positive nodes, mean (SD)	2.9 (7.7)
Min-Max	0-43
Adjuvant treatment (planned), n (%)	
Chemotherapy	19 (58)
Radiation	17 (52)
Legend: BCRL: breast cancer-related lymphedema. NA: not applicable	

At pre-surgery, there was excellent intra-rater reliability between CIR_{self_home} and $CIR_{self\_hospital}$ (ICC ≥ 0.94, 95% CI 0.87; 0.97, $p < 0.001$) and excellent inter-rater reliability between $CIR_{self\_hospital}$ and $CIR_{therapist}$ (ICC ≥ 0.95, 95% CI 0.88; 0.97, $p < 0.001$) for all points of measure and volume (Table 4.2). Similarly at post-surgery, there was excellent intra-rater reliability (ICC ≥ 0.96, 95% CI 0.93; 0.98, $p < 0.001$) and inter-rater reliability (ICC ≥ 0.91, 95% CI 0.76; 0.96, $p < 0.001$) (Table 4.2).

The 95%MDC for the CIR_{self_home} measurements ranged from 0.47cm to 1.62cm (Table 4.3). The 95%MDC for the VOL_{self_home} was 107 ml (5.7%) for the non-dominant arm and 115

ml (6.2%) for the dominant arm at pre-surgery, and 119 ml (6.3%) for the non-dominant and 113 ml (5.9%) for the dominant arm at post-surgery (Table 4.3). Participants reported ease of performing the self-measurements at home both at pre-surgery (8.2 ± 2.2) and at post-surgery (8.0 ± 1.9, $p = 0.33$).

Table 4. 2 Reliability of self-measured arm circumference

	Pre-surgery n = 33						Post-surgery n = 31					
	Dominant arm			Non-dominant arm			Dominant arm			Non-dominant arm		
Point of measure	ICC	95% CI	p-value	ICC	95% CI	p-value	ICC	95% CI	p-value	ICC	95% CI	p-value
Wrist												
Intra-rater	0.96	0.90;0.98	<0.001	0.94	0.87;0.97	<0.001	0.96	0.93;0.98	<0.001	0.97	0.93;0.99	<0.001
Inter-rater	0.96	0.93;0.98	<0.001	0.95	0.88;0.97	<0.001	0.92	0.69;0.97	<0.001	0.91	0.76;0.96	<0.001
10cm												
Intra-rater	0.97	0.93;0.99	<0.001	0.98	0.96;0.99	<0.001	0.97	0.94;0.99	<0.001	0.99	0.96;1.00	<0.001
Inter-rater	0.96	0.93;0.98	<0.001	0.97	0.94;0.99	<0.001	0.97	0.93;0.98	<0.001	0.95	0.90;0.98	<0.001
20cm												
Intra-rater	0.99	0.97;0.99	<0.001	0.99	0.98;1.00	<0.001	0.99	0.98;1.00	<0.001	0.99	0.97;1.00	<0.001
Inter-rater	0.99	0.99;1.00	<0.001	0.99	0.99;1.00	<0.001	1.00	0.99;1.00	<0.001	1.00	0.99;1.00	<0.001
30cm												
Intra-rater	0.99	0.98;1.00	<0.001	0.99	0.99;1.00	<0.001	0.99	0.98;1.00	<0.001	0.99	0.99;1.00	<0.001
Inter-rater	0.99	0.97;0.99	<0.001	0.99	0.97;1.00	<0.001	0.99	0.97;1.00	<0.001	0.99	0.96;1.00	<0.001
40cm												
Intra-rater	0.99	0.98;1.00	<0.001	0.99	0.99;1.00	<0.001	0.98	0.97;0.99	<0.001	0.99	0.95;1.00	<0.001
Inter-rater	0.99	0.98;1.00	<0.001	0.99	0.98;1.00	<0.001	0.99	0.98;1.00	<0.001	0.99	0.97;1.00	<0.001
Volume												
Intra-rater	0.99	0.97;0.99	<0.001	1.00	0.99;1.00	<0.001	1.00	0.99;1.00	<0.001	1.00	0.99;1.00	<0.001
Inter-rater	0.98	0.96;0.99	<0.001	0.99	0.98;1.00	<0.001	0.99	0.99;1.00	<0.001	0.99	0.98:1.00	<0.001

Legend: Intra-rater reliability of CIR_{self_home} and $CIR_{self\_hospital}$. Inter-rater reliability of $CIR_{self\_hospital}$ and $CIR_{therapist}$.
$CIR_{self\_hospital}$: self-measured circumference at hospital, $CIR_{therapist}$: therapist-measured circumference

Table 4. 3 Standard error of the measurement and minimal detectable change for self-measured arm circumference at home

	Pre-surgery n = 33						Post-surgery n = 31					
	Dominant arm			Non-dominant arm			Dominant arm			Non-dominant arm		
Point of measure	SD	SEM	MDC	SD	SEM	MDC	SD	SEM	MDC	SD	SEM	MDC
Wrist	1.09	0.22	0.60	1.06	0.26	0.72	0.99	0.19	0.55	0.98	0.17	0.47
10cm	2.47	0.43	1.19	2.17	0.31	0.85	2.10	0.36	1.01	2.20	0.22	0.61
20cm	2.38	0.24	0.66	2.07	0.21	0.57	2.41	0.24	0.67	2.22	0.22	0.61
30cm	3.58	0.36	0.99	3.20	0.32	0.89	3.33	0.33	0.92	3.55	0.36	0.99
40cm	4.23	0.42	1.17	4.27	0.43	1.18	4.13	0.58	1.62	4.63	0.46	1.28
Volume (ml)	431.37	43.14	115.01	385.02	38.50	106.72	408.01	40.80	113.09	429.35	42.93	119.01
Volume (%)	-	2.24	6.22	-	2.04	5.66	-	2.15	5.95	-	2.28	6.32

Legend: CIR_{self_home}: self-measured circumference at home, MDC: Minimal detectable change with 95% confidence, SEM: standard error of the measurement, SD: standard deviation.

Agreement between self-assessed and therapist-assessed shoulder ROM was good for flexion ($\kappa = 0.79$, $p < 0.01$) and abduction ($\kappa = 0.71$, $p < 0.01$) (Table 4.4). Among participants with limitations in shoulder ROM as determined by a PT, the median reduction was 10 degrees for flexion and 14 degrees for abduction.

Table 4. 4 Agreement between self-assessed and therapist-assessed shoulder ROM

	Agreement (κ) n = 29	**P-value**	**Limitations** (°)
			Median (25^{th}; 75^{th})
Flexion	0.79	< 0.01	10 (7; 27)
Abduction	0.71	< 0.01	14 (7; 52)

Legend: Cohen's kappa (κ) tested the agreement between self-assessed and therapist-assessed shoulder ROM. The degrees of limitations are reported for participants with reduced shoulder ROM (n =11 for flexion, n =12 for abduction). 25^{th} and 75^{th}: quartiles.

4.5 Discussion

This study demonstrated that self-measurement of arm circumference and active shoulder ROM is reliable among women who are scheduled to receive surgery for breast cancer. Further, self-measurement performed at home post-surgery is sensitive to detect small changes in arm circumference and therefore holds the potential to diagnose BCRL. This study confirmed the accuracy of self-measured arm circumference as previously demonstrated by our group in a laboratory setting[268]. Participants reported that the measurements were easy to learn and perform with support from the self-management resources and without in-person teaching by a PT. With the high recruitment and retention rates, self-managed surveillance for breast cancer related upper-body issues seems feasible to deliver as part of a hospital-based outpatient program.

This study demonstrated that self-measurement can detect small changes in arm circumference (95%MDC 0.5 to 1.6cm) as well as volume calculated from self-measurements

(95%MDC 5.6 and 6.3%). A 2cm[271] or 5 to 10%[272] interlimb difference or increase compared to pre-surgery measures in one circumference or volume measurement may indicate mild (grade I) BCRL. Only one study, by our group, has previously reported MDC for self-measured arm circumference[268]. Here we demonstrated 95%MCD of 0.3 to 1.6 cm for circumference and 4.6 to 6.9% for volume among participants with and without BCRL[268]. Similar ability to detect change is reported for therapist-measured arm circumference (95%MDC: 0.6 to 1.1cm[273]), and volume calculated from circumference measurements (95%MDC 2.6 to 9.4%[110]). As such, arm circumference measurement, performed by the patient or by a PT, may be used to diagnose BCRL at grade I or greater[274]. Subclinical BCRL (grade 0) with volume increase of ≤ 5% may not display sufficient or persistent volume increase to be diagnosed with circumference measurement or other measurement tools. Therefore, symptoms of heaviness and swelling should trigger a physical examination by a trained PT including observation, palpation and volumetric measurement to enable diagnosis of subclinical BCRL.

We employed a circumference measurement protocol of five points, however, other groups have proposed the idea of simplifying the measurement protocol further to facilitate easy self-monitoring of BCRL. Specifically, Hidding and colleagues tested the ability of using a single measurement point to detect BCRL[275]. They demonstrate a high correlation (r = 0.8) between the total arm volume and arm circumference measurement performed by a trained PT at 30cm proximal of the ulnar styloid[275]. Using this measurement location, a difference in circumference of 4% between arms holds good accuracy (Area Under the Curve = 0.94) and high sensitivity (0.85) and specificity (0.85) for detection of BCRL[275]. In the current study, we demonstrated 95%MDC of 0.89 to 0.99 cm which corresponds to 3.3 to 3.7% at the measurement point located 30cm proximal of the wrist. This indicates that self-measurement can detect small changes

(95%MDC < 4%) with the potential for detection of BCRL using this single measurement point. In line with this, Stout and colleagues demonstrated that changes in circumference at the measurement points at 10cm, 20cm and 30cm proximal to the ulnar styloid can predict early onset of BCRL[256]. More research would be needed confirm these findings and test if circumference measurement, performed by the patient or by a PT, at fewer than 5 measurement points or even a single measurement point is robust enough to diagnose BCRL. However until more research is conduced, the use of a single measurement point for diagnosis of lymphedema is not recommended[274].

In this study, 12 of 29 (41%) with unilateral surgery presented with limitations in shoulder ROM at post-surgery with good agreement ($\kappa \geq 0.71$) between the self- and PT assessments. Participants with limitations in shoulder ROM had a median of 10 to 14 degrees reductions in ROM compared to the unaffected side. This provides some insight into the clinical decision-making around when shoulder ROM should be categorized as "impaired". The results of this study suggest that reductions in shoulder flexion of 10 degrees and shoulder abduction of 14 degrees is considered relevant and meaningful both for the patient and the PT and thus should trigger further assessment and treatment. This study is the first to test the agreement between self-assessed and therapist-assessed shoulder ROM among women with breast cancer. Previous studies have tested the agreement between self-assessed and physician-assessed shoulder ROM using questionnaires[276] or a physical (self-)examination with assessment and reporting of own ROM[277,278] among patients undergoing shoulder surgery. They report moderate agreement (κ = 0.51 for abduction and 0.50 for flexion[277]) and mean difference between the patient and physician assessments of 4 and 6 degrees for shoulder flexion and abduction[278], respectively. In oncology as well as orthopedic rehabilitation, tracking and quantifying patients progress after

surgery without the need for in-person visits has substantial implications for logistics and resource allocations for long-term follow-up of patients in clinical settings or by research teams. While more work is needed, this simple method of physical self-examination of shoulder ROM could potentially be applicable to monitor recovery after surgery and identify patients in need for physical therapy treatment.

Strengths of this study include testing of the self-measurement protocol in a clinical setting as part of an out-patient hospital-based program. Patients who were scheduled for surgery for breast cancer were systematically invited to participate. As a result, participants in this study have good generalizability, with a range of education levels, and family incomes, and were ethnically representative of the geographical setting of the study. The excellent reliability and participant-reported ease of performing the measurements demonstrate that women of different demographic characteristics can learn self-measurement easily and perform it accurately across time. However, as a limitation, the self-measurement resources were offered in addition to usual care at SMH which included therapist-measured arm circumference. As such, participants had the choice to do self-measurement in addition to the therapist-measurements or decline participation and only receive the therapist-measurements. Recruitment and feasibility would likely be different at a clinical site that does not offer therapist-measurement and where self-measurement would be the only option for surveillance for upper-body issues. This approach should therefore be tested at a site that does not have a surveillance program in place. Further, this study tested the reliability and feasibility of self-measurement using only one post-surgery measurement. Consequently, the ability of self-measurement to detect the onset of BCRL was not tested and to do so would require longer follow-up (a minimum of 12 months[68]) and a sufficiently powered study. Future research is needed to evaluate the long-term sustainability of

performing self-managed surveillance, the ability to accurately detect BCRL and impaired shoulder ROM, and how this approach to surveillance can lead to timely and effective management to reduce the prevalence of chronic upper-body issues among women with breast cancer.

4.6 Clinical implications

New modes of delivering prospective surveillance for breast cancer-related upper-body issues are needed to extend the reach of current PT services within oncology care. Self-managed surveillance for BCRL using simple, user-friendly measurement protocols, such as an inexpensive tape measures and short video guide, holds great promise. In addition to improving the reach, self-managed prospective surveillance encourages and empowers patient stakeholders in the management of their own health. This self-measurement approach provides PTs and other clinicians with the opportunity to facilitate accurate surveillance for upper-body issues among patients at risk and initiate appropriate care at the appropriate time.

4.7 Conclusion

Self-measured arm circumference is reliable and can easily be learned and performed by women before and after surgery for breast cancer. Changes in arm volume of $\geq 6\%$ can be detected by self-measurement and should warrant further assessment by a PT to establish a diagnosis of BCRL. There is good agreement between self-assessed and therapist-assessed shoulder ROM which represents an opportunity for self-managed surveillance of the recovery after surgery for breast cancer.

Chapter 5: Room for Improvement of Breast Cancer Rehabilitation Services: A Focus Group Study of Survivors' and Professionals' Experiences and Preferences for Rehabilitation Care Delivery

5.1 Synopsis

Little is known about the translation of national guidelines into clinical rehabilitation programs in Canada. This study aimed to explore the experiences of breast cancer survivors (BCSs), rehabilitation professionals (RPs) and breast surgeons (BSs) on current rehabilitation services including preferences for care delivery, specific ways to promote early detection and timely management of upper-body issues, and attitudes towards self-managed surveillance and rehabilitation. Thirty-five BCSs, 29 RPs and 5 BSs were recruited from across British Columbia, Canada, and participated in 11 semi-structured focus groups. BCSs completed a survey about rehabilitation services received and experience of upper-body issues. Data was analyzed using content analysis. The results revealed that all BCSs had chronic upper-body issues (mean 4.5 unique issues). Three categories emerged from the qualitative data that captured participants' concern and wish for care: 1) *Cut the cancer out and goodbye* described current care; 2) *You have to look out for yourself* described the consequences of current care, and 3) *In a perfect world* described ideas for improving care. BCSs expressed worry and uncertainty in their solo-management of upper-body rehabilitation. The services reported did not emphasize preventative strategies nor enabled early detection and timely management, and were in need of revamping to increase equity of care. Suggestions included reorganizing the timing of patient education and

improving the quality of and access to rehabilitation services by elevating the knowledge among healthcare professionals and providing multimodal self-management resources.

A version of this chapter has been submitted for publication as Rafn BS, Midtgaard J, Camp PG, Campbell KL. Room for improvement of breast cancer rehabilitation services: A focus group study of survivors' and professionals' experiences and preferences for rehabilitation care delivery. This work was also presented as a poster and oral presentation at the International Conference for Physical Therapists in Oncology held in Amsterdam, the Netherlands, June 2018.

5.2 Introduction

Rehabilitation is recommended to help cancer survivors regain functional independence during and after oncology treatment and to mitigate subsequent disability[152]. While national and international cancer guidelines recommend that rehabilitation is offered from the point of diagnosis, rehabilitation services are often not integrated into cancer care services. In Canada, 1 in 8 women will develop breast cancer during their lifetime, and approximately 82% of women diagnosed with breast cancer survive for at least ten years[279]. BCSs generally experience a wide spectrum of physical sequelae from surgery to remove the tumour and associated cancer treatment, such as upper-body pain and tightness, limited shoulder ROM, reduced upper-body muscle strength and function[58], and BCRL[78], together referred to as upper-body issues. To mitigate the development of these issues, clinical guidelines in Canada recommend that BCSs begin an early post-surgery upper-body rehabilitation exercise program[153,154]. Further, recommendations from experts in the field are to have pre-surgery measurements taken of arm circumference and shoulder ROM[166,280] to serve as baseline measures and to use for early

detection of upper-body issues after surgery. However, there is a lack of data on the translation of these recommendations into clinical care in Canada.

Formal oncology rehabilitation programs are scarce in Canada and are predominantly delivered through out-patient programs in hospitals located in larger cities (population > 500,000)[156]. In addition, Canadian healthcare professionals report that existing programs do not meet the rehabilitation needs of their patients with the main barriers being: 1) access to care; and 2) availability of resources (space and staffing)[156]. The shortfall between the Canadian rehabilitation capacity and the prevalence of breast cancer means that only a minority of BCSs have access to oncology rehabilitation.

To understand the needs and barriers for providing quality rehabilitation, an in-depth exploration of the experiences of BCSs and healthcare professionals on current rehabilitation care delivery is needed. Furthermore, the specific preferences with respect to upper-body rehabilitation programming have yet to be thoroughly explored, but are crucial considerations in ensuring the feasibility and acceptability of future rehabilitation programs for this population. The aim of the current study was therefore to explore the experiences among BCSs, rehabilitation professionals and surgeons on current rehabilitation services within the public setting. We also sought preferences for rehabilitation care delivery including how to promote early detection and timely management of upper-body issues and explored the attitudes towards self-managed surveillance and rehabilitation.

5.3 Materials and Methods

5.3.1 Design

Focus groups along with questionnaires was chosen to allow data source triangulation[281] to understand BCSs' experiences as well as to quantify the rehabilitation care received. Focus groups were chosen to allow facilitation of the group discussions, promote interactions between participants, and allow the first author to interact and respond to participants' comments. This allowed us to explore and compare the experiences and preferences from participants at the different sites and among the different target groups[282]. The study is reported consistently with the consolidated criteria for reporting qualitative studies (COREQ) checklist[283].

5.3.2 Participants and procedures

In British Columbia (BC), healthcare is delivered through five geographically based Health Authorities (HAs). The Research Ethics Boards of each of the five HAs in BC approved this study (H17-00928). Purposive sampling was used to obtain perspectives from three target groups: 1) breast cancer survivors (BCSs); 2) rehabilitation professionals (RPs) (specifically PTs, nurses, lymphedema therapists) working with rehabilitation of BCSs; and 3) breast surgeons (BSs). We aimed to recruit 30 BCSs, 20 RPs and 5 BSs. We considered this sample size would provide saturated information to meet the study aims. In each of the five HAs we conducted one focus group with BCSs and one with RPs. A focus group with BSs was conducted in only one HA.

BCSs who had participated in previous studies within the last authors' (KC) laboratory were emailed with information about the study and invited to contact the first author (BSR) if

they were interested in participating. In addition, bulletins were posted at hospitals across BC, which provided information about the study and invited BCSs to contact the first author if they were interested in participating. Last, participants were recruited through word-of-mouth. Maximal variation was sought for BCSs in area of residence, age, income and education. A snowball sampling strategy was applied for RPs and BSs. RPs working with oncology rehabilitation at the larger hospitals in each HA were invited to participate and asked to invite colleagues who manage rehabilitation for BCSs to contact the first author if they were interested in participating. In addition, RPs from private practices with specialty in breast health were identified from the Physiotherapy Association of BC website and invited via email to participate. The BSs in one HA were recruited through word of mouth. The first author contacted all potential participants via telephone or email to confirm interest and eligibility, as well as to schedule the focus group.

Eligibility criteria for BCSs were: 1) 18 years or older; 2) currently undergoing or within 5 years of treatment completion for any stage breast cancer; and 3) being able to understand and speak English. Eligibility criteria for RPs were: 1) licensed PT, nurse or lymphedema therapist in BC; 2) having ≥ one year of clinical experience that included care of BCSs; 3) being able to understand and speak English. Eligibility criteria for BSs were: 1) practicing breast surgeon in BC; 2) having ≥ one year of clinical experience that included care of BCSs; 3) being able to understand and speak English.

5.3.3 Data collection and analysis

Informed consent was obtained from all participants. BCSs completed sociodemographic (i.e., age, area of residence, education, income), medical (i.e., cancer treatment), and

rehabilitation services and needs questionnaires (i.e., education and rehabilitation treatment, use of self-management strategies, experience of upper-body issues) (Appendix J). RPs and BSs completed a brief questionnaire about setting of work and years of experience. All questionnaires were developed for the study specifically. After completing the questionnaires, participants took part in a semi-structured focus group. Focus groups took place at meeting rooms in hospitals in each of the HAs and were held between September 2017 and December 2017. Participant local travel costs were reimbursed, but no payment was provided for participation. The first author (BSR) conducted all focus groups using a guide with open-ended questions developed based on the research aim (Appendix K). A theory was not used to guide the study, rather the study was conducted to increase our understanding of the perspectives on self-managed surveillance and rehabilitation and use this to inform the development of future programs. The questions therefore focused on participants' perspectives on current rehabilitation services, beliefs and attitudes towards self-management strategies for upper-body issues, and ideas and preferences towards modes of delivery for rehabilitation services. Probes were used to obtain clarification or more detailed information when needed. Field notes were not used, nor were the questionnaire answers used to guide the group discussion. Female volunteers were present during the focus group to support the collection of questionnaires.

Group discussions were audio and video recorded, transcribed verbatim and analysed using conventional content analysis[284] and researcher triangulation[281]. As preparation, the overall sense of the data and initial meaning was identified from a preliminary review of the transcripts (BSR, JM). NVivo 12 software (QSR International, Melbourne, Australia) was then used to organize the raw data through open coding by one researcher (BSR) during repeated readings of the transcripts. In the next step, the data were grouped and the number of categories were reduced by

combining similar headings into broader categories with additional categories interpreted deductively[285]. These categories were sorted according to pre-defined topics from the focus group guide to address the study aims (i.e., perspectives on current rehabilitation services, and preferences towards delivery of care). Preliminary results were reported to participants via a webinar to allow for feedback and validation of the reporting. Preliminary categories were analysed and refined following discussion (BSR, JM, PC, KC) to identify common and divergent issues. Subcategories were refined and final categories were named using empirically-derived words and organized under one overarching category.

5.4 Results

The sample consisted of 35 BCSs, 29 RPs, and 5 BSs. BCSs had a mean age of 54.2 (min: 34; max: 78) years and were a mean of 1.9 (SD 2.9) years after surgery for breast cancer (Table 5. 1). RPs represented 18 clinical sites with a mean of 9.1 (SD 7.4) years of experience with oncology rehabilitation (Table 5. 2). Twenty-five (86%) were PTs. BSs had a mean of 21.6 (SD 10.4) years of experience and each performed an average 191.0 (SD 146.3) surgeries for breast cancer per year. The eleven focus groups ranged from 46 to 78 minutes, with a mean length of 66 minutes. Some participants had previously participated in research by the team and thus knew the first author (BSR). An additional fourteen BCSs, eleven RPs and two BSs were interested but unable to participate primarily due to scheduling difficulties and were not interviewed.

Table 5. 1 Characteristics of women with breast cancer

	n = 35
Age, mean (SD)	54.2 (10.2)
Min-Max	34-78
Ethnicity, n (%)	
Caucasian	28 (80.0)
Asian	4 (11.4)
Other	3 (8.6)
Region of residence, n (%)	
North	8 (22.9)
Island	9 (25.7)
Interior	6 (17.1)
Fraser	4 (11.4)
Vancouver	8 (22.9)
City population, n (%)	
Metropolis >500,000	6 (17.1)
Urban 50,000-500,000	23 (65.7)
Town <50,000	6 (17.1)
Marital status, n (%)	
Married	17 (48.6)
Common Law	3 (8.6)
Separated	3 (8.6)
Widowed	1 (2.9)
Divorced	5 (14.3)
Never Married	6 (17.1)
Education, n (%)	
Some High school	1 (2.9)
Completed High school	2 (5.7)
Some University/college	8 (22.9)
Completed University/college	15 (42.9)
Some Graduate School	2 (5.7)
Completed Graduate School	7 (20.0)
Family income in CAN $, n (%)	
<20,000	2 (5.7)
20-39,999	5 (14.3)
40-59,999	4 (11.4)
60-79,999	3 (8.6)
80-99,999	6 (17.1)
>100,000	15 (42.9)
Employment status, n (%)	
Disability	6 (17.1)
Retired	8 (22.9)
Part time	7 (20.0)
Full time	13 (37.1)
Temporarily Unemployed	1 (2.9)
Smoking status, n (%)	
Never Smoked	20 (57.1)
Ex-Smoker	12 (34.3)
Occasional Smoker	1 (2.9)
Regular Smoker (smoke every day)	2 (5.7)
Living arrangement, n (%)	
Live with spouse/other family member	25 (71.4)

	n = 35
Live alone	10 (28.6)
Breast cancer stage, n (%)	
0	2 (5.7)
I	2 (5.7)
II	8 (22.9)
III	7 (20.0)
IV	2 (5.7)
Unknown	14 (40.0)
Recurrence/second breast cancer, n (%)	6 (17.1)
Breast cancer surgery, n (%)	
Mastectomy	26 (74.3)
Lumpectomy	9 (25.7)
Reconstructive surgery, n (%)	
No	16 (45.7)
Implant	11 (31.4)
TRAM flap	2 (5.7)
NA	5 (14.3)
Lymph node dissection, n (%)	
Axillary lymph node dissection	17 (48.6)
Sentinel lymph node dissection	16 (45.7)
Neither /unknown	2 (5.7)
Number of lymph nodes removed, mean (SD)	9.66 (7.84)
Number of positive lymph nodes, mean (SD)	2.23 (3.12)
Post-surgical complications, n (%)	
Infection	4 (11.4)
Drainage issues	7 (20.0)
Seroma	8 (22.9)
Hematoma	0 (0)
Adjuvant therapy, n (%)	
Chemotherapy	23 (65.7)
Radiation therapy	25 (71.4)
Time since surgery, years, mean (SD)	1.9 (2.9)
Legend: TRAM: transverse rectus abdominis, NA: not applicable.	

Table 5. 2 Characteristics of rehabilitation professionals and breast surgeons

Rehabilitation professionals	**n = 29**
Age, mean (SD)	45.0 (10.7)
Min-Max:	26-65
Highest degree attained, n (%)	
Physical therapist (BSc)	18 (62.1)
Physical therapist (MSc)	7 (24.1)
Lymphedema therapist	2 (6.9)
Registered nurse	2 (6.9)
Breast cancer continuing education, n (%)	17 (58.6)
Region of residence in BC, n (%)	
North	6 (21)
Vancouver Island	6 (21)
Interior	7 (24)
Fraser	6 (21)
Vancouver	4 (14)
Primary practice setting, n (%)	
Hospital-based outpatient	11 (37.9)
Inpatient acute care	10 (34.5)
Private practice	8 (27.6)
Settings represented, n	18
Hospitals	10
Private clinics	8
Years worked as RP, mean (SD)	18.9 (10.3)
Min-Max:	1-40
Years worked in oncology rehabilitation, mean (SD)	9.1 (7.4)
Min-Max:	1-25
Hours/week in patient care, mean (SD)	30.1 (9.4)
Min-Max:	10-40
Cancer-related patients/week, mean (SD)	6.4 (8.7)
Min-Max:	0-30
Percentage of hours/week involving cancer-related conditions, mean (SD)	20.1 (28.7)
Min-Max:	0-100
Time point to deliver treatment*, n (%)	
Pre-surgery	7 (24.1)
Within 1st month of surgery	16 (55.2)
Within 6 months of surgery	15 (51.7)
6-12 months post-surgery	13 (44.8)
>12 months post-surgery	7 (24.1)
Breast surgeons	**n = 5**
Years of experience, mean (SD)	21.6 (10.4)
Breast cancer surgeries/year, mean (SD)	191.0 (146.3)
Legend: RP: rehabilitation professional, BC: British Columbia, * RPs could choose more than one answer, so % is above 100%.	

Specific to BCSs experience with oncology rehabilitation, pre-surgery measurements for shoulder ROM was reported by two (6%) BCSs and measurement of arm circumference was reported by six (17%) BCSs (Table 5. 3). Seven (20%) BCSs reported never receiving education

(i.e., a pamphlet) about upper-body rehabilitation. Nine (26%) BCSs reported being referred to rehabilitation by a healthcare professional, while fourteen (40%) reported self-referring to rehabilitation, and twelve (34%) reported not receiving any rehabilitation. Five (14%) BCSs reported experiencing upper-body issues prior to surgery, while 35 (100%) reported currently experiencing upper-body issues, with a mean 4.5 (min: 1; max: 9) unique issues. Most common issues were upper-body tightness (n = 33, 94%), numbness (n = 23, 66%), and muscle strength impairment (n = 20, 57%). Fourteen (40%) BCSs had developed BCRL. Thirty-two (91%) BCSs reported self-managing upper-body issues and eighteen (56%) reported they had sufficient support to do so.

Table 5. 3 Rehabilitation services and needs among women with breast cancer

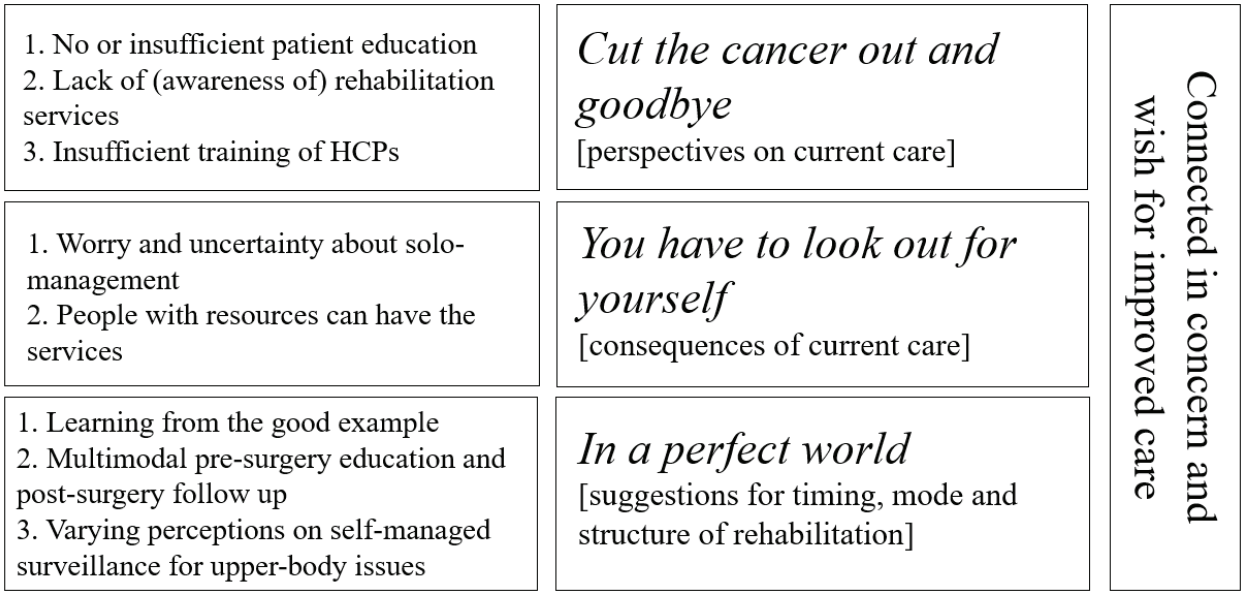
	n = 35
Pre-surgery measurement, n (%)	
Shoulder ROM	2 (5.7)
Performed by	
Self-measured	1 (2.9)
Physical therapist	1 (2.9)
Arm circumference	6 (17.1)
Performed by	
Self-measured	2 (5.7)
Physical therapist	2 (5.7)
Nurse	2 (5.7)
When was rehabilitation education received*, n (%)	
Never	7 (20.0)
Pre-surgery	15 (42.9)
Within first month post-surgery	8 (22.9)
Later	8 (22.9)
Who delivered rehabilitation education*, n (%)	
No one	7 (20.0)
Physical therapist	13 (37.1)
Surgeon/oncologist	6 (17.1)
Chiropractor	1 (2.9)
Other (massage therapist, nurse)	15 (42.9)
Referred to physical therapy, n (%)	
By healthcare professional	9 (25.7)
Self-referred	14 (40.0)
Not referred	12 (34.3)
Reason for referral*, n (%)	
Shoulder ROM	17 (48.6)
Upper-body muscle strength	10 (28.6)

	n = 35
Lymphedema	12 (34.3)
Scar tissue	5 (14.3)
Cording	1 (2.9)
Peripheral neuropathy	1 (2.9)
General exercise	7 (20.0)
Setting of rehabilitation care, n (%)	
Private practice	9 (25.7)
Public facility	7 (20.0)
Combination of private and public	4 (11.4)
Alternative or complementary treatment^, n (%)	23 (65.7)
Self-managed upper-body issues, n (%)	
during treatment	32 (91.4)
after treatment	32 (91.4)
Sufficient support to self-manage upper-body issues	18 (51.4)
Upper-body issues, n (%)	
Prior to surgery	5 (14.3)
Currently	35 (100.0)
Current upper-body issues, n (%)	
Tightness	33 (94.3)
Numbness	23 (65.7)
Muscle strength	20 (57.1)
Shoulder ROM	18 (51.4)
Pain	16 (45.7)
Skin changes (fibrosis/scarring)	15 (42.9)
Lymphedema	14 (40.0)
Cording	10 (28.6)
ADL	7 (20.0)
Skin infection/cellulitis	1 (2.9)

Legend: * Participants could choose more than one answer, so % is above 100%.
^Examples of alternative/complementary treatment: Massage therapy, diet, mindfulness, manual lymph drainage, yoga, meditation. ROM: range of motion. ADL: activities of daily living

From the qualitative data with all three target groups, the overarching category identified was *United in concern and wish for improved care*, which reflected participants' shared concern and dissatisfaction with the public system where BCSs were ill equipped to manage upper-body issues, and the unifying wish to improve rehabilitation care. Moreover, three main categories, each with sub-categories, were identified: 1) *Cut the cancer out and goodbye*; 2) *You have to look out for yourself;* and 3) *In the perfect world* (Figure 5.1). The following section presents a description of each category with reference to illustrative quotes.

Figure 5.1 Coding tree with categories and sub-categories



I Cut the cancer out and goodbye

This category offers an understanding of the experiences of and perspectives on the public rehabilitation services. Quotes to illustrate this category are presented in Table 5.4. BCSs and RPs discussed how treatment for cancer (surgery, adjuvant therapies) and rehabilitation (education, self-management resources, referral to physical therapy) were disconnected. BCSs experienced the time of surgery as being in a "revolving door" with a short stay at the hospital without priority of education about rehabilitation. Specifically, BCSs strongly emphasized a lack of education about how to identify and manage upper-body issues, and a lack of referral to physical therapy. BSs and RPs working in public settings expressed concern with the limited education provided, and the absence of a streamlined approach to ensure early identification of issues and timely rehabilitation treatment.

No or insufficient patient education

BCSs discussed emotionally that they had received no or insufficient education about how to manage upper-body issues after surgery (Table 5.4). They felt that the medical team was focused on removing the tumour, while little emphasis was put towards the consequences of surgery. Most BCSs had received education about rehabilitation only once in the form of a pamphlet with post-surgical upper-body exercises. Some BCSs had received verbal education from a PT (n = 13, 37%) or oncologist (n = 6, 17%) before they left the hospital while others were given the exercise pamphlet without verbal education (n = 7, 20%) (Table 5.3). BCSs shared that the verbal education often was delivered quickly when the survivor had just undergone surgery, was on pain medication and unable to retain the information.

Specifically for BCRL, BCSs spoke about an absence of or conflicting information about risk behaviours, information about own risk of BCRL, ways to prevent or detect BCRL, or where to go if they suspected having BCRL. Their high levels of worry about BCRL did not match the level of information provided verbally by the medical team or included in the pamphlet.

Similarly, the RPs discussed that the current delivery of patient education is not ideal due to limited time the day of surgery. The RPs expressed that although patients often are not susceptible to receive education just after surgery it is not wasted completely as the patients are provided with a pamphlet.

Lack of (awareness of) public rehabilitation services

Rehabilitation services were consistently reported to be lacking (Table 5.4). Some BCSs did not qualify to receive rehabilitation due to the nature of their issues or the type of treatment received. Some sites solely offered rehabilitation to those for whom the upper-body issue

prohibited receiving radiation therapy. Similarly, the BSs shared that options for referral into public facilities were limited, especially for BCSs living outside the metropolitan area, which hindered or delayed rehabilitation treatment.

Insufficient training of healthcare professionals

Awareness of the importance of rehabilitation as well as expertise in delivering oncology rehabilitation among some healthcare professionals was expressed by the BCSs to be limited (Table 5.4). Lack of recognition of upper-body issues often prohibited referral into the public rehabilitation services. Further, some PTs in public settings were perceived to lack education into oncology rehabilitation as they were perceived to be at a loss when upper-body issues were complex.

Taken together, this category illustrate that the current patient education and rehabilitation services are perceived to be inadequate to support self-management due to no or insufficient education, along with limited availability (or awareness) of services, and knowledge in the medical team about the importance of timely identification and skillful management of upper-body issues.

Table 5. 4 Quotes to illustrate the first category *"Cut the cancer out and goodbye"*

Sub-category	Quote
No or insufficient patient education	*It's just about cut the cancer out. Cut it out and then you're good to go. You're fine now, bye bye.* (BCS, HA4, P2)
	It was very quick...and I'm kind of half stoned, I'm on pain medication, I was feeling nauseated, and you're giving me this information to retain. (BSC, HA1, P8)
	They say after you've had a surgery not to sign any documents for at least 24 hours. So, let's not tell patients important information. Like how dare you come in when I'm half corked out of my tree and lay all this information on me and now I'm responsible for it?! (BSC, HA2, P4)
	They see a physiotherapist and get the brochure of exercises. But they often come back and don't know what's going on. One session is not enough for many of them to understand. (BS, HA3, P1)
	Often, it's as they're running out the door, so you're running through this booklet of stuff and they want to leave. It's a very small snippet of time. (RP, HA4, P2)
Lack of (awareness of) rehabilitation services	*I was never made aware of, never offered, never signed up for or referred to any kind of rehab.* (BCS, HA3, P2)
	I was never told of anything. I know there's physiotherapist at the hospital, but I've never heard of breast cancer patients using them. It was never offered. (BCS, HA4, P1)
	There's no public [rehabilitation]. Unless you go to the hospitals and the hospitals will never get back to them. They take the referral and say, "we'll call you back", and I'll see the patients 6 months later and they're still waiting on a call from physio. And then I'm very embarrassed that I even wasted my time. And the similar is true at [name of public facility in Vancouver], their wait times are lengthy. (BS, HA3, P2)
Insufficient training of HCPs	*I don't think we can educate patients until we educate the people who are looking after the patient. I think the therapist and the nurses know exactly what's going on, but the problem is the patient is going to the doctor, they're going to their family doctor, their surgeon, their oncologist and when they blow that off and say, "oh you're fine", that has a huge weight. I think we have to back up and look at that.* (RP, HA1, P1)
	*Once I really had trouble they [the RPs] were stumped with what to do with me and had nothing to offer. (*BCS, HA5, P1)

Legend: BCS: Breast cancer survivor, BS: Breast surgeon, RP: Rehabilitation professional, HA: Health Authority. P: participant. Example of coding: BCS, HA3, P2: breast cancer survivor from health authority 3, and participant 2 in the focus group.

II You have to look out for yourself

This category offers an understanding of the consequences of the current delivery of patient education and rehabilitation services within the public system. Quotes to illustrate this category are presented in Table 5.5. BCSs described worry and uncertainty when self-managing upper-body issues, disparities in access to existing rehabilitation services and consequently delayed start of rehabilitation treatment when issues were well-established and difficult to manage. BCSs spoke about their way "out of the system" into the private settings. RPs and BSs expressed concern with the "two-tiered" system, where only people with resources get the services.

Worry and uncertainty about solo-management

The lack of rehabilitation services illustrated by the limited patient education and collaboration with a RP, left BCSs in a situation of solo-management, where they solely were responsible for managing the rehabilitation. BCSs described that this solo-management led to feelings of uncertainty and worry (Table 5.5). BCSs were worried about how to manage the rehabilitation exercises and unsure if they were helpful or harmful. The lack of information left the BCSs ill equipped to identify issues and seek appropriate care. BCSs were unsure of what to consider "normal" and often accepted living with upper-body issues as a new normal.

People with resources can have the services

RPs viewed the system to be "two-tiered", where BCSs with resources (i.e. personal initiative, ability to ask questions and seek information, support from social community, financial resources or extended health insurance to pay for treatment in private settings) can

access services while BCSs without those resources are either left without treatment or received treatment at a later stage. Further, a concern with the "unethical" system with inequity of rehabilitation care was expressed which was viewed to hinder timely treatment especially for patients with fewer resources (Table 5.5).

BCSs with resources spoke about their "way out of the system" specifically, the barriers associated with identifying specialized RPs and paying for the services as well as the positive experiences with receiving care in private settings. BCSs with access to rehabilitation services in private settings spoke about feelings of luck of own privileges and at the same time deep concern about what other (less fortunate) women do. One breast surgeon shared how she sometimes must work around the system to address the inequity of care.

In order to receive timely rehabilitation and avoid developing chronic issues BCSs reported that it was necessary to "be your own advocate" or have good social support. RPs highlighted the lack of emphasis on prevention and the need for early identification of complications. The lack of early identification and subsequent delayed start of treatment often led to the development of chronic upper-body issues that treatment cannot resolve.

Collectively, this category reveals that BCSs are worried and uncertain in their solo-management of upper-body issues. Participants perceive the consequences of current care to be a lack of or delayed referral to rehabilitation when upper-body issues are chronic. The "lucky" BCSs who have the resources to be their own advocates and pay for treatment by specialized RPs escape into the private settings. Both BCSs, RPs and BSs express concern with those less fortunate.

Table 5. 5 Quotes to illustrate the second category *"You have to look out for yourself"*

Sub-category	Quote
Worry and uncertainty about solo-management	*Is it tight because I should be working on it or is it tight because I shouldn't be doing this? That's what you're always worried about, am I going to make it worse.* (BCS, HA4, P2)
	I was left confused. They talk about doing these exercises right after surgery, but some of them were far too difficult. I had immediate reconstruction. So, when I tried to do exercises on my own, I had no idea if I was tearing stitches, causing harm to implants, things hurt, and I didn't know what was good pain or what was bad pain. (BSC, HA3, P3)
	I didn't know what I needed (BCS, HA2, P1)
People with resources can have the services	*It's a two-tiered system. If people have money I can send them off to private practice to some very, very experienced people. But if they have no money, that is a major problem.* (RP, HA1, P1)
	Sometimes we'll trick, if there's a Vancouver address for patients who are really desperate, then sometimes they can access the Vancouver services but that's crazy. And that's not equitable. (BS, HA3, P3)
	People have more or less ability to do research and access resources. That's where my heart just breaks for patients who don't know how to go and find that out for themselves. (BCS, HA3, P3)
	You have to look out for yourself. I could see why people end up with problems down the road and they could have been caught. (BCS, HA2, P7)
	A lot of the patients that get referred to me are already in stage 2 lymphedema. Same thing with cording and stuff, it's already a big issue and sometimes you can help them, sometimes you can't, depending on how long they've dealt with it. (RP, HA5, P1)

Legend: BCS: Breast cancer survivor, BS: Breast surgeon, RP: Rehabilitation professional, HA: Health Authority. P: participant. Example of coding: BCS, HA3, P2: breast cancer survivor from health authority 3, and participant 2 in the focus group.

III In a perfect world

This category offers ideas and suggestions for improving patient education and access to rehabilitation services. Quotes to illustrate this category are presented in Table 5.6. This includes suggestions for timing, mode and structure of patient education and follow-up supported by multimodal self-management resources as well as resources for self-managed surveillance.

The good example

One hospital had a rehabilitation program that differed significantly from the other sites. This program included a pre-surgery education class for all BCSs and planned follow-up appointments at 1, 6, and 12 months post-surgery. The pre-surgery education class included information about BCRL and instruction in the rehabilitation exercises, provision of a pamphlet to support self-managed rehabilitation, and therapist-administered measurements of shoulder ROM and arm circumference. Those measurements were repeated at the post-surgery follow-up appointments to enable detection of upper-body issues. The RPs working at this hospital considered their patients to be fortunate and the BCSs who had received care at this hospital were satisfied with the program (Table 5.6).

Multimodal pre-surgery education and post-surgery follow-up

RPs emphasized the importance of early detection, and management of upper-body issues and discussed ways to facilitate this. A different timing of patient education was needed and a pre-surgery patient education session was considered to be ideal to allow RPs to "plant the seed" about the importance of rehabilitation (Table 5.6). Benefits of having a dialogue (instead of written material only) was highlighted to ensure that BCSs who are too shy to speak up also get the information and are prepared to manage the rehabilitation. Another benefit was the opportunity to initiate rehabilitation exercise before surgery for those with pre-existing upper-body issues.

RPs discussed different modes of delivery of patient education, including a video-conference or a video guide, for sites where scheduling difficulties (i.e., few surgeries for breast cancer or long commute for patients) would prohibit a group class. In addition, the importance of

pre-surgery measurement of arm circumference was discussed including ways to include such assessments without adding extra visits for the patient. Similarly, ways of facilitating distance-based follow-up at set intervals were discussed to support self-management, monitor the recovery and screen patients to provide rehabilitation services to those in greater need. While face-to-face appointments were viewed to be ideal, distance-based follow-up by phone was considered to be beneficial for screening for upper-body issues.

Varying perceptions on self-managed surveillance for upper-body issues

There were varying perceptions regarding self-managed surveillance for upper-body issues. Some RPs viewed a self-assessment tool to be beneficial and be more likely to happen than therapist-led monitoring. It was discussed that measurements could also be performed by a spouse for people who were overwhelmed with the situation. Some BCSs noted that it would be hard to do self-measurement of arm circumference while others thought that self-managed surveillance for shoulder ROM and arm circumference would be great to improve access and track own recovery. In contrast to the perspectives from RPs and BCSs, BSs were concerned about introducing self-managed surveillance and worried it would be difficult for patients and evoke anxiety (Table 5.6).

Overall, participants discussed the need for better timing of patient education and more follow-up using different modes of delivery to improve access to services. Different ways of screening patients were discussed to identify those in need for rehabilitation treatment.

Table 5. 6 Quotes to illustrate the third category *"In a perfect world"*

Sub-category	Quote
The good example	*That's where we have our strength because they're seen at pre-admission, 1, 6, and 12 months after surgery, and if there're any problems along the way then we will initiate treatment. But I think the biggest component is having that pre-admission where they're given the education, and in the one month follow ups it's explained. So, I think that our patient population is quite fortunate to have that service available to them.* (RP, HA5, P3)
	I was very impressed with the way they have it set up here. If this could exist everywhere, that would be ideal. (BCS, HA5, P2).
Multimodal pre-surgery education and post-surgery follow up	*A pre-op class would be the perfect scenario, because you could hit the highlights in the book and get them to do the exercises when they're well so they know what to do. It's about planting the seed.* (RP, HA3, P3)
	Another benefit of the class would be to have a dialogue…clear up some of those questions. And that hits all the folks that are too shy to speak up. (RP, HA1, P2)
	Ideally, we'd see them before. Because if they already have a mobility issue that shoulder is not going to get any better with surgery. (RP, HA2, P1)
	I have to ask my patients if they're having any pre-op shoulder problems because certainly after surgery it gets worse temporarily or permanently. (BS, HA3, P1)
	Maybe if they can't come into the class, we can video-conference. Even something they could pull up online that would be in a video form if they can't attend (RP, HA4, P5)
	In a perfect world I think they could be checked up with at certain time points where you call them, or they come in for a physical check-up which would be even better. And you can go over the education, what to look for, how to measure, educational videos of how they could do it themselves would be ideal. (RP, HA2, P2)
	I think we could provide better service to patients and we could auto-screen those in greater need versus those that don't need it. (BS, HA3, P2)
	I think if coming face-to-face isn't possible, just having somebody do a phone call follow up to screen if there's any questions, even things that we may not realize could be an issue and if it's identified then, then it doesn't compound and compound and compound (BCS, HA5, P2)
Varying perceptions on self-managed surveillance for upper-body	*I think that a self-assessment tool, whether it's through an app or a video, if it's followed up with person contact can be really beneficial.* (RP, HA1, P5)
	For some people they're just happy to be alive and it's probably too much to take on. But if we could provide some resources for them, they could get their spouse to measure their arm. (RP, HA4, P7)
	The more self-based it is the more chance it's going to happen. (RP, HA1, P1)
	I don't think I'm qualified. That would be hard. (BCS, HA5, P4)

Sub-category	Quote
	I think it is a great idea having some basic ways to measure shoulder range of motion that women can use as self-checks. And if you're noticing "oh I'm stuck here, and my other arm is going here", that would be a reason to go. Especially for women who don't have access. (BCS, HA5, P2)
	I would have appreciated having someone teach me and for me to do the measurements, so I had an idea. Like even draw a line, measure, draw a line. At least you're monitoring it and you've got it if you need it. (BCS, HA4, P3)
	I think it would be difficult for patients to do arm measurements with the tape measure. (BS, HA3, P1)
	I think you're going to foster anxiety if you ask the patients to self-measure. (BS, HA3, P2)

Legend: BCS: Breast cancer survivor, BS: Breast surgeon, RP: Rehabilitation professional, HA: Health Authority. P: participant. Example of coding: BCS, HA3, P2: breast cancer survivor from health authority 3, and participant 2 in the focus group.

5.5 Discussion

This study explored the perspectives and consequences of the breast cancer rehabilitation care that is currently available in this specific public healthcare system and offers suggestions for ways to improve early detection and management for upper-body issues that likely have implications for care delivery across a variety of healthcare systems. Participants' accounts revealed that patient education is important, and a lack of education does not provide BCSs with the skills and confidence to undertake effective self-management. Further, when awareness of available rehabilitation services is limited the result is that rehabilitation treatment is often initiated only when upper-body issues are difficult or impossible to resolve. All BCSs in this study experience chronic upper-body issues which points to the consequences of the identified drawbacks with the current models of care. Participants indicated that even within a public healthcare system that strives to have one-tier quality care for all individuals, the current system is in fact two-tiered. Only BCSs with resources receive rehabilitation and most commonly

through self-referral into the private healthcare settings. Participants in this analysis described a need for pre-surgery education and post-surgery follow-up, provision of multimodal self-management resources, and improved awareness of existing public and private oncology rehabilitation facilities. Self-managed surveillance resources can be added for those who are motivated. In order to develop effective rehabilitation programming to address the high prevalence of chronic upper-body issues in this population, these factors must be addressed.

Based on our findings, cancer treatment is still perceived to focus only on diagnosis, treatment, and symptom alleviation, while rehabilitation of functional and physical problems are underrecognized and undertreated[286]. This is a paradox because physical disability including upper-body issues, and not the cancer diagnosis itself, is often a leading cause of distress among BCSs[287,288]. In our study, twenty percent of BCSs reported receiving no information on rehabilitation exercises, 34% had never seen a rehabilitation professional for treatment or education, and only a minority had pre-surgery measurements taken of shoulder ROM and arm circumference. This is not in concordance with the national and provincial recommendations[154,280]. While most public facilities in BC provide BCSs with a pamphlet about rehabilitation following surgery[289], the timing and quality of patient education must be improved to meet the recommendations.

This gap between recommendations and clinical practice highlights the need to consider other strategies, such as self-management programs, to increase the reach and access of evidence-based rehabilitation. Self-management is defined as "the systematic provision of education and supportive interventions by healthcare staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support"[189]. To begin to address this, we have

developed self-management upper-body rehabilitation[290] and surveillance[268] resources and demonstrated them to be feasible and acceptable to include in public rehabilitation facilities[290,291] and able to support BCSs in performing measurements for upper-body issues on themselves in a reliable and valid manner[268,291]. Future research will establish if integrating such self-management resources into clinical programs can enable early detection and management and lower the prevalence[136,180,247] and complexity[179] of upper-body issues as demonstrated by therapist-administered surveillance programs.

To enable successful self-managed upper-body rehabilitation, it is fundamental to provide BCSs with the knowledge and skills to perform rehabilitation exercises and identify when more treatment by RPs is needed. Importantly, BCSs with poor health literacy ("ability to access, understand, evaluate and communicate information"[292]) may need more practical communication from the health professionals[234] than just receiving a pamphlet. As such, structured-, culturally appropriate and patient specific education is superior than ad hoc instruction or generalized information[293]. Our results indicate that quality patient education is not provided in BC due to insufficient time and inappropriate timing of delivery. Furthermore, information provision alone is unlikely to be sufficient to motivate to sustainable rehabilitation behaviour and improve clinical outcomes in upper-body function[234]. In addition to written material, supportive video guides or verbal instructions are relevant to equip people to manage their health[234].

Participants described inequity of access to rehabilitation and concern with the patients unable to be their own advocates. This echoes existing research indicating that disparities in access to rehabilitation cause underutilization of existing services[224] and development of chronic upper-body issues among BCSs, especially for patients of low income[225,226]. One of the many determinants of inequalities in health concerns utilization of existing health services[294]. The

scoping review by Grabovschi and colleagues[295] demonstrated a direct correlation between an increase of vulnerability factors (i.e., lack of health insurance, low level of education, low financial resources) and the escalation of healthcare disparities. Thus, vulnerable BCSs with inability to request referral to rehabilitation treatment may not be aware of nor use the existing services. While Canada has publicly-funded healthcare[296], where oncology rehabilitation is covered by public health insurance if delivered in hospitals or specialized medical facilities, the marked shortfall of public oncology rehabilitation programs[156,289] is a major contributor to the described inequality of care. In other countries of universal healthcare, the utilization of supportive care (i.e., oncology nursing, psychology and physical therapy) by cancer survivors is quite equitable and explained by patient-perceived need (i.e., lower physical or mental health) and clinical factors (i.e., tumour stage and adjuvant therapies)[297]. Given the contextual challenges with great distances between specialized medical facilities in Canada, new approaches to delivery of rehabilitation care are needed to address this inequity.

Lack of knowledge about the benefits of oncology rehabilitation among patients and referring clinicians may further aggravate the underuse of existing services[224]. The participating BCSs and RPs expressed a need to educate referring clinicians in order to improve their ability to identify patients in need for rehabilitation. Only 9 (26%) BCSs were referred to rehabilitation by a healthcare professional, while 14 (40%) self-identified the need and self-referred themselves to rehabilitation. Oncologists are often not successful in identifying supportive care needs among patients nor referring to relevant services[246,298,299]. As a result, a negligible number of survivors access physical therapy or other cancer rehabilitation services, with lowest utilization among survivors of low education[299]. If the referring clinicians are unaware of the need for rehabilitation or unaware of the existing rehabilitation services, it is unlikely that BCSs will be referred to

them[300]. The need to educate RPs into oncology rehabilitation is acknowledged by the American Physical Therapy Association, who has developed a program for specialization in oncology physical therapy, recognized by the American Board of Physical Therapy Specialties, with the first certified PT anticipated in spring 2019. This accreditation will likely make it easier for PTs to stay up-to-date on evidence and best practice, strengthen their confidence in complex management, cultivate their expertise and knowledge[301] which may greatly benefit American survivors. In contrast, Canada has no such specialization program and to date only two Canadian PTs have been certified clinical specialists in oncology by the Canadian Physiotherapy Association[302]. Together, this underscores the need for educating referring clinicians and RPs in Canada, but also underpins the importance of educating survivors to self-identify and self-manage issues confidently and effectively.

Participants shared ideas for ways to improve the public rehabilitation services and move from solo-management towards a collaborative rehabilitation management. Inspired by the positive experiences at the hospital that employed a prospective surveillance model of care delivery[166], participants highlighted a need for pre-surgery education and post-surgery follow-up to guide BCSs in detecting and managing upper-body issues in partnership with RPs. Simple initiatives such as re-organizing the timing of services by providing patient education before surgery instead of the day of surgery could have substantial impact on patients' ability to retain the information. This would enable the RPs to: 1) prepare BCSs into what to expect from treatment (i.e., what is "normal"); 2) educate about BCRL; 3) demonstrate the rehabilitation exercises; 4) clarify any uncertainties; 5) identify patients with pre-existing shoulder pathologies who are at elevated risk of developing chronic upper-body issues after surgery[303]; 6) provide self-management rehabilitation and surveillance resources (written and video supported); and 7)

perform measurements of shoulder ROM and arm circumference (or teach patients to self-measure) to refer back to after surgery and use for early detection of issues. Such simple initiatives could potentially alleviate the worry and uncertainty currently experienced by BCSs and support them better in managing the rehabilitation. Mode of delivery for education and follow-up could be group settings, one-on-one either in-person or via telephone, or via educational videos depending on setting and patient preferences. Finally, BCSs and referring clinicians need information about the available public rehabilitation services, specialized private RPs, and community-based resources (i.e., exercise or support groups) to improve awareness of and access to these services.

The strengths of this study stem from the combination of data from focus groups and questionnaires from three distinct key stakeholders, namely BCSs, RPS, and BSs. This approach allowed us to quantify the rehabilitation services and needs as well as understand the perspectives and consequences of the services among the three key groups. The group discussions were successful in engaging participants and likely revealed richer and clarified data compared to individual interviews. While the external validity is good given the sampling strategy and wide inclusion criteria, the possibility of self-selection bias cannot be ruled out as those with more positive or negative experiences or those who are uncomfortable to engage in group discussions may not have chosen to participate. Lastly, the suggestions towards delivery of rehabilitation care to improve access should be further investigated and refined using a discrete choice experiment to guide the selection and tailoring of program elements that will maximize update, acceptability and likelihood of implementation.

5.6 Conclusion

Multiple chronic upper-body issues were reported by many of the participating BCSs, who expressed worry and uncertainty in their solo-management. This study revealed that the participating BCSs were actively engaged in managing upper-body issues but that the current rehabilitation services need revamping to give BCSs greater confidence for self-management and to increase the equity of care. In addition, the current approach to healthcare delivery does not emphasize preventative strategies nor initiatives to enable early detection and timely management of upper-body issues. Participants highlighted a need for reorganizing the timing of patient education and improving the quality of and access to rehabilitation services by elevating the knowledge among healthcare professionals and providing multimodal self-management resources. Future programming must address these concerns and acknowledge that partnership is needed to connect care for cancer survivors.

Chapter 6: Conclusion

6.1 Summary of Findings

Breast cancer-related upper-body issues are prevalent despite being treatable by timely physical rehabilitation as summarized in Chapter 1. There is an urgent need to develop and implement programs and create policies to protect BCSs from developing chronic upper-body issues. The research questions investigated in this dissertation were based on curiosity and reflections about why so many survivors develop chronic upper-body issues after treatment for breast cancer, and reflections around delivery of rehabilitation care and the wish to promote early detection of upper-body issues and equal access to physical rehabilitation. To date, there are few examples of surveillance and specialized rehabilitation programs in Canada[156] and internationally and even fewer that are accessible to survivors without personal or financial resources or that can reliably reach those living in rural and remote areas.

There were some overall visions for cancer rehabilitation research and service delivery described in Chapter 1[157,158]. These suggested directions have been used to inform our own research. First, we wanted to address the need for development of rehabilitation programs in collaboration with local communities and supported by technology to allow access for survivors[157]. Further, with the limited number of facilities that deliver specialized physical rehabilitation for people with cancer or specific to BCSs in Canada[156], we wanted to evaluate resources to support performance of evidence-based rehabilitation exercises at home. Second, we wanted to address the need for development of brief and valid patient-administered outcome measures[158], which is important to accurately measure changes in key outcomes of interest such

as arm circumference or shoulder ROM. Finally, we hoped to address the call for research into ways to overcome challenging contexts such as rural and remote communities[158] by minimizing the need for in-person teaching and instruction when using our new resources.

The research projects in this dissertation are carried out in Denmark (Chapter 2) and British Columbia (BC), Canada (Chapter 3 to 5). Denmark and BC are comparable in terms of population size (5.7 million vs. 4.9 million), and breast cancer incidence (4.600 vs. 3.500), and 5-year survival rates (85% vs. 88%), respectively[279,304]. Further, both Canada and Denmark have publicly funded healthcare, including rehabilitation services following surgery for breast cancer when provided at public facilities. Thus, the findings and conclusions drawn from the studies can be generalized across the two settings to some extent. However, an important difference between the two locations is the population density (average 131[305] vs. 4[306] people per km^2 in Denmark and BC, respectively) with great variation within BC[306], which calls for testing of multiple approaches to rehabilitation care delivery to enable access to the public services, particularly in BC.

Chapter 2 reports on the development and feasibility evaluation of the BRECOR program. We developed the program elements (website, pamphlet and clinical assessment tool) to change the mode of delivery of the existing rehabilitation services in 11 municipalities in the Capital Region of Denmark. Our hope was that by providing multimodal self-management resources including video guides and printed information, we would better support participants in performing the exercises at home correctly, frequently and comfortably, and keep them motivated to maintain the behaviour for an extended period of time (i.e., 12 weeks in the feasibility evaluation). Further, as most PTs working in community-based rehabilitation centres in Denmark (and Canada) are not specialized in managing breast cancer-related upper-body

issues, we hoped that the developed clinical assessment tool for PTs would support the therapists in performing a comprehensive upper-body assessment and ensure a prescription of rehabilitation exercises that would have the most benefit for the individual. We found the developed patient and therapist resources to be feasible to use in various community-based rehabilitation facilities based on our pre-specified targets. Participants reported benefit from performing the rehabilitation exercises and improved their upper-body functioning. The study displayed adequate uptake and helped us understand the capacity, including the time required by PTs to undertake the assessment and provide the individualized rehabilitation exercise prescription, needed to move forward in a Canadian context.

The BRECOR program utilized therapist-administered assessments of shoulder ROM and arm circumference, and we became curious if women could do these assessments on themselves to further minimize the need for in-person visits. There is a growing consensus that frequent assessments using a prospective surveillance model is the ideal approach for management of BCRL[118,182,183]. However, the surveillance assessments involve patient burden for some, including potential out-of-pocket healthcare costs, as well as require in-person visits to specialized facilities and this approach to care is thus not accessible for all survivors. To date, all published studies have focused on therapist-administered assessment for shoulder ROM and BCRL. It has not been evaluated if survivors can perform these measurements on themselves. Therefore, research was needed to determine the reliability, validity and attitudes towards self-measurement.

In the studies described in Chapters 3 and 4, we sought to fill this research gap. While a number of expensive objective tools exist to measure arm circumference (i.e., perometry) or

accumulation of extracellular fluid as indication of the development of lymphedema (i.e., bioimpedance spectroscopy), a therapist-administered measurement of arm circumference using a simple tape measure continues to be the most used method of assessment to monitor for onset or change in extent of BCRL in clinical settings due to its simplicity and low cost. We set out to develop a protocol that would allow women to measure themselves that was easy to learn and easy to perform and did not require expensive equipment. First, we developed written and video-supported material to enable distance-based delivery of the education and demonstrated self-measurement of arm circumference to be reliable and valid among BCSs in a research setting (Chapter 3). Importantly, participants reported that self-measurements were easy to do and did not increase worry about developing or worsening BCRL. Following this, we felt it was important to confirm the reliability in a clinical setting among women scheduled for surgery for breast cancer and include self-assessment for shoulder ROM (Chapter 4). Pre-surgery measurement is key to enable detection of subtle volume changes in the affected arm after surgery as indicative of subclinical BCRL. However, we appreciate that this is an overwhelming time for many women with decisions around treatment and uncertainty about the future. Despite these challenges, the study displayed good uptake (79%) and retention (94%) for a prospective self-measurement program, excellent reliability of the circumference measurements, good agreement of the shoulder ROM assessments, and participants reported it was easy to learn and perform the measurements.

Before moving on to developing an intervention to address breast cancer-related upper-body issues to be evaluated in British Columbia (potentially similar to the BRECOR program with the addition of self-measurement resources for BCRL and shoulder ROM), we wanted to

understand the current services and the need for more or different services. Across different geographic locations, a number of factors may influence the feasibility of specific rehabilitation programs and the likelihood of participants adhering to a given program. Thus, exploring women's experiences and preferences for upper-body rehabilitation and tailoring rehabilitation service delivery to these preferences would be an important step to inform the development of a feasible and effective surveillance and rehabilitation program. Further, understanding the experiences and preferences of rehabilitation professionals and breast surgeons is key for developing a program that is clinically acceptable for the healthcare professionals who provide the services or refer patients to them.

From the focus groups (Chapter 5), we learned that survivors experienced a profound lack of information about rehabilitation, were unsure about how to identify upper-body issues, and experienced barriers in finding and paying for care by a rehabilitation professional with expertise in oncology rehabilitation. Only a minority of the survivors reported in a questionnaire that they had received the recommended measurements of shoulder ROM and arm circumference at pre-surgery or education and treatment by a PT. We learned that the rehabilitation professionals and breast surgeons are concerned with the current "two-tiered" system, the lack of emphasis on prevention or early detection of issues, and the limited availability of rehabilitation services in public facilities. We also gained a better understanding of what resources are needed, and key considerations around timing and modes of delivery of services. Furthermore, it was clear that most survivors and rehabilitation professionals interviewed would value a self-managed surveillance program for early and consistent identification of issues, while breast surgeons were more hesitant regarding such programs. This hesitation could potentially be

caused by the fact that breast surgeons usually provide services that do not involve self-management for patients (i.e., surgery to remove the tumour or breast reconstruction surgery). We hypothesize that breast surgeons would be less hesitant regarding a self-managed surveillance program if presented with research evidence to demonstrate the reliability, validity and acceptability of such an approach.

6.2 Study Contributions, Strengths and Limitations

The contributions of each study to this dissertation as a whole, and the strengths and limitations of each of the research papers have been described in detail in each of the study Chapters (2 to 5). This body of work advances the understanding of current upper-body rehabilitation services following surgery for breast cancer in British Columbia and offers new approaches to delivery of upper-body surveillance and rehabilitation. The developed resources for self-managed surveillance and rehabilitation in Chapters 2 to 4 were found to be feasible and acceptable and were reported by participants in Chapter 5 to address an urgent need for better support in performing rehabilitation exercises at home and detection of issues in need for treatment by a healthcare professional. Referring back to the two initial questions that guided the development of research questions for this dissertation (page 37), the work has contributed with new approaches to delivery of surveillance and rehabilitation that may enable early detection and improve access to care. It remains unknown if these approaches are effective in preventing the development of chronic breast cancer-related upper-body issues. This is an important future direction, and will be discussed in section 6.3.

There is an ongoing need to engage understudied populations, including survivors across a wide demographic range (i.e., participants of various age, socioeconomic status, education,

ethnicity, and area of residence) and extend research beyond the metropolitan areas. We therefore aimed to address this in the projects. The research presented in Chapter 2 was conducted in 11 municipalities located within one health authority (the Capital Region) in Denmark to test the feasibility of integrating the new resources in various clinical settings. In Chapter 3, the first data collection session took place at participants' home unsupervised by a PT. This approach was chosen to evaluate the ability of a participant to complete the measurement procedure using teaching by the educational materials only. We believe that this distance-based delivery of patient education strengthens the usability of the self-measurement protocol and the ability to reach those who will not be able to attend an in-person session. Similarly, in Chapter 4, we chose to conduct the study outside Vancouver and sought to include participants that represented the geographical context of Surrey in terms of ethnicity and sociodemographic characteristics. We therefore developed the educational material in Punjabi in order to improve reach of individuals who use this as their first language, which represents a larger proportion of individuals who live in the catchment area for Surrey Memorial Hospital. The use of consecutive recruitment resulted in successful recruitment of a sample of women with Punjabi as their first language. This approach also allowed us to recruit women with a variation in level of education and income. This gave us confidence that self-managed surveillance for upper-body issues was feasible and accurate in a clinical setting and acceptable for a heterogenous sample of survivors that were reflective of the patients seen in this hospital. Finally, in Chapter 5, we purposefully sampled participants living in the different health authorities of British Columbia, with various ages, levels of education and income. It was likely that survivors and healthcare professionals represented across these different groups may have different experiences and preferences for rehabilitation delivery. For example, prior research has demonstrated that BCSs who live in rural

or remote areas in Canada prefer to receive home-based programs and counseling about physical activity[307]. The similar could be true for preferences regarding education about rehabilitation exercises and we therefore assumed that participants living or working in rural areas would have reported similar preferences for receiving/providing home-based rehabilitation education and follow-up appointments using distance-based approaches to rehabilitation service delivery. Further, prior research has demonstrated that specialized oncology rehabilitation programs in Canada are mostly located in metropolitan areas (population of > 500,000 citizens)[156], and we therefore assumed that participants living in the metropolitan area of British Columbia would report having received more services in line with the guidelines and would potentially share positive experiences in accessing in-person rehabilitation services. However, in contrast, we found a unified concern with the current care regardless of geographical location and a shared wish to improve equity of care. These results speak to the importance of continuing the work in this field to improve rehabilitation services in British Columbia.

A main strength of this dissertation is the conception of four original research projects that integrate research knowledge and the end users (i.e., breast cancer survivors, rehabilitation professionals and breast surgeons). Further, the use of mixed methods (i.e., program development and feasibility evaluation, repeated psychometric testing of a novel patient-administered outcome measure, and qualitative focus groups with the three key target groups) along with multiple settings for conducting the projects (i.e., laboratory and clinical settings) was invaluable for gathering knowledge to inform future studies.

Based on the importance of using reliable and valid outcome measures that are psychometrically tested among BCSs highlighted in Chapter 1, we prioritized the use of

objective or well-validated measures in this research. For example, in Chapter 2, our choice to use a clinical assessment by a trained PT was based on the consensus in previous research and clinical settings that this is ideal for a comprehensive evaluating of clinical outcomes. Furthermore, to capture patient-reported outcomes, the QuickDASH was selected, over other potential instruments, since this instrument has been validated among BCSs[308]. However, the lack of established cut off points for the QuickDASH to define upper-body issues requiring intervention limits the interpretability and it would be desirable to determine the proportion of participants who move from having limitation to not having limitations in upper-body functioning after participating in the BRECOR program or others. In Chapter 3 and 4, we chose to use a combination of objective (perometry in Chapter 3) and well-validated (therapist-administered circumference measurement in Chapter 3 and 4) measures for comparison with the self-measurements which was important for increasing confidence in the accuracy of self-measurements.

There are several overall limitations to this work that should be taken into consideration when interpreting the results, and applying them to the development of future research interventions or clinical programs. Firstly, the research in Chapter 2 was conducted in public rehabilitation centres located in the Capital Region of Denmark. Denmark is a densely populated small country with universal publicly-funded healthcare which includes rehabilitation and exercise for cancer survivors delivered by PTs free of charge during treatment for cancer. Thus, environmental barriers, such as distance to rehabilitation facilities and out-of-pocket cost of services, are much less of a factor than they would be in other countries. Since the BRECOR program only requires one face-to-face visit, it is likely that the program elements would be of

much greater benefit in locations with fewer public healthcare services and particularly the website might be of more use in rural and remote areas.

Another limitation is that we did not prospectively follow women for an extended period of time in Chapter 4 and therefore cannot determine the sensitivity of self-measurement in detecting BCRL or shoulder ROM impairments. This is an important limitation and recommendations for future research regarding this will be discussed in section 6.3.

Finally, our studies did not reach other key populations in British Columbia such as first nations BCSs, Chinese speaking BCSs, or male BCSs. More work is needed to adopt the developed resources to match the needs of these groups to further extend reach and access to care.

6.3 Future Directions and Recommendations

Based on the literature reviewed in Chapter 1 and our findings (Chapters 2 to 5), several recommendations for future research programs and policy work can be made. There is now emerging evidence from predominantly observational studies for the benefit of prospective surveillance in detecting and enabling timely management for BCRL[168–179]. However, in Canada (or Denmark), there is no streamlined approach for measurement and management of BCRL likely due to a paucity of research evidence into effective, scalable and accessible surveillance programs. More work is therefore needed to evaluate the long-term sustainability of performing self-managed surveillance for BCRL, the ability to accurately detect BCRL, and if this approach to surveillance can lead to timely and effective management to reduce the prevalence of chronic BCRL. This work requires a large-scale rigorous randomized controlled trial with several year of

follow-up to establish the effectiveness and cost-effectiveness of self-managed prospective surveillance compared to therapist-led prospective surveillance and a control group on the development of BCRL. It would have significant value to identify BCRL early if it can prevent the progression instead of waiting until the structural changes are irreversible and require life-long self-management with daily (and nightly) wear of compression, frequent treatment sessions with lymphedema therapists, and the subsequent physical[309], emotional[310], and financial[311] impact. A self-managed surveillance program is likely more clinically feasible and accessible for survivors across regions than a hospital-based therapist-administered surveillance program, and thus scalable if documented effective.

In addition to knowledge creation, knowledge translation activities are also needed to improve the awareness of: the continued high prevalence of issues, also after the introduction of less invasive surgical procedures; the lack of compliance with surveillance and rehabilitation guidelines and consequently worry and uncertainty currently experienced by the patients; and the evidence of the reliability and validity of self-managed surveillance for upper-body issues. Such translational activities could include passive dissemination strategies (i.e., publication of rehabilitation research in surgical journals), and active strategies, such as educational meetings (i.e., presentation of research evidence at the provincial breast tumour surgical meetings, and education sessions for rehabilitation professionals, patients and their relatives at BC Cancer), identification of opinion leaders (i.e., partnering with local clinicians (i.e., oncologists, surgeons, physical therapists, oncology nurses) for research and translational projects), and audit and feedback of compliance to guidelines[312]. Similar strategies have previously been used to increase

awareness of research evidence among Canadian colorectal surgeons and to create change by improving compliance with guideline recommendations[313].

BCSs with upper-body issues (limitations in shoulder ROM, muscle strength, upper-body functioning, or pain) before surgery for breast cancer are at elevated risk of developing chronic upper-body issues after surgery[303]. Particularly limitations in shoulder ROM are common before surgery for breast cancer[314]. The rehabilitation professionals and breast surgeons interviewed in Chapter 4 also raised a concern with the BCSs who have pre-existing upper-body issues. This calls for development and testing of (self-management) prehabilitation programs informed by pre-surgery measurements of key outcomes in upper-body functioning. Oncology prehabilitation has been defined as a "process on the continuum of care that occurs between the time of cancer diagnosis and the beginning of acute treatment, includes physical and psychological assessments that establish a baseline functional level, identifies impairments, and provides targeted interventions that improve a patient's health to reduce the incidence and the severity of current and future impairments"[315]. To date, very little attention has been paid to this window in time and the potential benefits of initiating an exercise program. Santa Mina and colleagues have proposed a five-pillar paradigm to develop a comprehensive breast cancer prehabilitation program (including general conditioning exercise, targeted upper-body and core exercises, nutritional guidance, stress reduction, and smoking cessation)[316]. They propose that such programs could potentially be useful in reducing the number of women who develop chronic upper-body issues after surgery for breast cancer. In a 2018 systematic review, Yang and colleagues summarized the little literature available to date on the effect of physical prehabilitation programs for BCSs on upper-body recovery[317]. They include four observational

studies and two feasibility or pilot randomized studies and report that physical prehabilitation programs might optimize shoulder ROM, muscle strength, general fitness and reduce pain following surgery for breast cancer. However, the review includes studies by our group[180] and others[136], that are testing a prospective surveillance approach and not a prehabilitation program. This area remains an opportunity for exploration for future research potentially by utilizing the paradigm proposed by Santa Mina et al[316].

The suggestions towards delivery of care to improve equity of access to rehabilitation services in British Columbia described in Chapter 5 should be further investigated and refined. Collaborations with clinicians, healthcare decision-makers and health economists in the development of surveillance and rehabilitation programs to be tested in pragmatic clinical trials should be encouraged in such future research[318,319]. This may allow development of programs that match the unique contextual factors of the settings with selection and tailoring of program elements that will maximize update, acceptability and likelihood of implementation[320]. Moreover, this will allow collection of information about risks, benefits and cost of programs as they would occur in routine clinical practice[319]. Such programs should likely include a range of rehabilitation services, in addition to upper-body rehabilitation services, to meet the diverse needs of survivors[157].

Lastly, research in this field has several limitations. First, the absence of an agreed-upon definition for breast cancer-related upper-body issues, which weakens the prevalence rates described in Chapter 1. Second, the limited knowledge into the etiology and pathophysiology of BCRL hampers accurate diagnosis and staging of the condition. An absolute (ml) or relative (%) arm volume increase is currently used in guidelines for categorization[75–77], however this

approach is not ideal as the total arm volume includes bone, muscle, and fat mass as well as body water. Thus, increases in arm volume may be explained by changes in body composition rather than the onset of BCRL. Furthermore, this has limited the ability to obtain prevalence rates of breast cancer-related upper-body issues in British Columbia, as information about BCRL or other issues is not systematically captured in administrative health data. Establishing a definition using the Delphi technique[321] or a discrete choice experiment[320] would be of great value to evaluate effect of research interventions or clinical programs across different studies/settings. A definition will also be useful to determine the prevalence of BCRL, muscle strength or shoulder ROM limitations, limitations in performing ADL, or chronic pain among survivors in Canada for comparison with the prevalence in other places. Such prevalence data might also strengthen the argument that physical rehabilitation services are needed and that efforts are warranted to detect and manage issues early to prevent chronic issues.

6.4 Conclusion

This dissertation describes a carefully developed series of scientific studies designed to test new approaches to delivery of surveillance and rehabilitation for breast cancer-related upper-body issues, consisting of a self-managed rehabilitation program, a protocol for self-managed surveillance for BCRL and shoulder ROM limitations, and qualitative study to understand the preferences for surveillance and rehabilitation care delivery. This dissertation lays the groundwork for future large-scale rigorous randomized controlled trials to establish the effectiveness and cost-effectiveness of the new approaches to care delivery at reducing the burden of chronic upper-body issues and improving quality of life among women with breast cancer.

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Appendix A The Clinical Assessment Tool for the BRECOR Program

KONKLUSION OG PLAN

Konklusion

Hjemmeøvelser

Plan

- Hold ☐
- Individuelt ☐
- Hold og individuelt ☐
- OBS individuel (Pt. henvender sig 3.gang på et hold) ☐
- Individuelt efter strålebehandling ☐

Evt. bemærkninger:

CENTER FOR KRÆFT & SUNDHED KØBENHAVN

UNDERSØGELSESSKEMA TIL SCREENING EFTER BRYSTKRÆFTOPERATION

DATA

Navn: _____

Fødselsdato: _____

Operationstype: _____

Operationsdato: _____

Efterbehandling: _____

Undersøgelsesdato: _____

Fysioterapeut: _____

Komplikationer fra operationsdato til i dag

	Ja	Nej	
Smerter umiddelbart efter op.	☐	☐	Lokalisation: _____
Seromtømning	☐	☐	Antal gange: _____
			Sidst tømt: _____
Misfarvninger	☐	☐	
Blødning	☐	☐	
Infektion	☐	☐	

SUBJEKTIVT

* Patientrapporteret smerte 0-10 (i dag): _____
* Patientrapporteret oplevelse af stramhed/stivhed i operationsområdet 0-10 (i dag): _____

Tidligere skulder-/nakkeproblemer Ja ☐ Nej ☐

Dominerende hånd hø ☐ ve ☐

Andet: _____

* ARMOMFANG

	Venstre:	Højre:	Venstre:	Højre:
Punkt 1:	_____	_____	_____	_____
Punkt 2:	_____	_____	_____	_____
Punkt 3:	_____	_____		

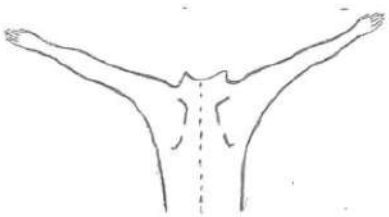
OBJEKTIVT

Inspektion

		Ja	Nej	
Holdning:	Sekret	☐	☐	Lokalisation:
Scapula:	Ødem	☐	☐	Lokalisation:
Cicatrice:	Misfarvning	☐	☐	Lokalisation:
	Infektion Obs!	☐	☐	

STÅENDE

Hudfoldetest



Bevægelighed

	Nedsat højre:	Nedsat venstre:		Ikke nedsat ve.	Ikke nedsat hø.	Moderat nedsat ve.	Moderat nedsat hø.	Meget nedsat ve.	Meget nedsat hø.
Rotation af Cerv. Col.	☐	☐	* Skulderfleksion	☐	☐	☐	☐	☐	☐
Rotation af columna	☐	☐							

	Ja	Nej		* Muskeltest	Ikke nedsat ve.	Ikke nedsat hø.	Moderat nedsat ve.	Moderat nedsat hø.	Meget nedsat ve.	Meget nedsat hø.
Scapuladysfunktion	☐	☐	_____							
Cording	☐	☐	_____	M. latissimus dorsi	☐	☐	☐	☐	☐	☐
Nerveværv - symptomer	☐	☐	_____	M. serratus ant.	☐	☐	☐	☐	☐	☐

LIGGENDE

Holdningsinspektion: _____

_____

_____

_____

	Ikke nedsat ve.	Ikke nedsat hø.	Moderat nedsat ve.	Moderat nedsat hø.	Meget nedsat ve.	Meget nedsat hø.
* Udadrotation i skulderled:	☐	☐	☐	☐	☐	☐

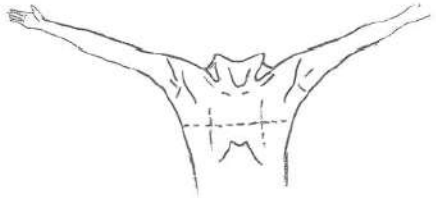
* Muskeltest

M. pectoralis major

Claviculære del	☐	☐	☐	☐	☐	☐
Sternale del	☐	☐	☐	☐	☐	☐

Test af n. medianus:	Ikke nedsat ve.	Ikke nedsat hø.	Moderat nedsat ve.	Moderat nedsat hø.	Meget nedsat ve.	Meget nedsat hø.
Abd skulder,	☐	☐	☐	☐	☐	☐
Flex håndled,	☐	☐	☐	☐	☐	☐
Sup. albue,	☐	☐	☐	☐	☐	☐
Udrot. skulder,	☐	☐	☐	☐	☐	☐
Ext. albue	☐	☐	☐	☐	☐	☐

Forskydelighed på forside



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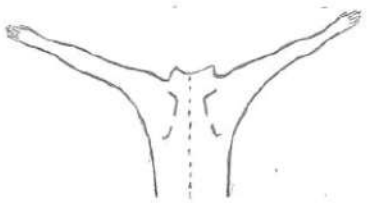
☐	☐	☐

Forskydelighed på ryg



Ikke nedsat	Moderat nedsat	Meget nedsat
☐	☐	☐

Information og øvelser til kvinder, der har fået fjernet en knude i brystet

CENTER FOR KRÆFT & SUNDHED KØBENHAVN

KØBENHAVNS KOMMUNE
Sundheds- og Omsorgsforvaltningen

EFTER DIN OPERATION

Denne pjece er til dig, der har fået fjernet en knude i brystet. Heri finder du information, råd og øvelser, som kan hjælpe dig efter din operation.

I tiden efter operationen kan du opleve forandringer i operationsområdet, skulderen og armen.

Forandringerne kan opstå på forskellige tidspunkter efter operationen, og de mest almindelige er:

- Nedsat bevægelighed i skulderen
- Stramhed over brystet, i armhulen, i armen og på ryggen
- Smerter
- Hævelse
- Uhensigtsmæssig brug af musklerne omkring skulder og ryg
- Stikken og prikken i arm og hånd

Vores erfaring er, at et dagligt træningsprogram kan afhjælpe mange af disse forandringer.

Det er en god idé at udføre øvelserne samtidig med dit forløb med eventuel kemo- og strålebehandling.

Når du har prøvet øvelserne nogle gange, vil du lidt efter lidt bedre kunne mærke dine reaktioner og derfor lettere kunne målrette dine øvelser.

HVOR OFTE SKAL DU TRÆNE?

Det er meget individuelt, hvordan dit væv reagerer efter operationen og den eventuelle strålebehandling.

- Hvis dit væv er knudret, stramt og hårdt, anbefaler vi, at du laver øvelser 1-2 gange dagligt.
- Hvis dit væv er blødt og smidigt, dit ar er pænt og din bevægelighed er god, kan du nøjes med at lave øvelser et par gange ugentligt.

Pjecen tager udgangspunkt i Kirsten Tørsleffs øvelseshæfte, som kan downloades på www.kirstentoersleff.dk.

Før du går i gang:

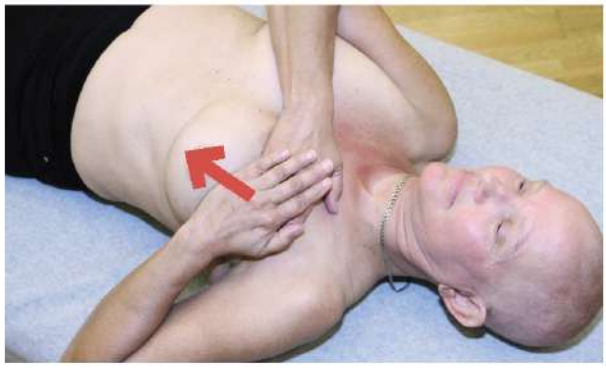
- Læg dig i en behagelig stilling med begge skuldre i underlaget
- Huden skal være bar og uden creme
- Tag et par dybe vejrtrækninger
- Det må gerne stramme under øvelserne, men det må ikke gøre ondt, hverken mens du udfører dem eller efterfølgende!

VÆVSBEHANDLING

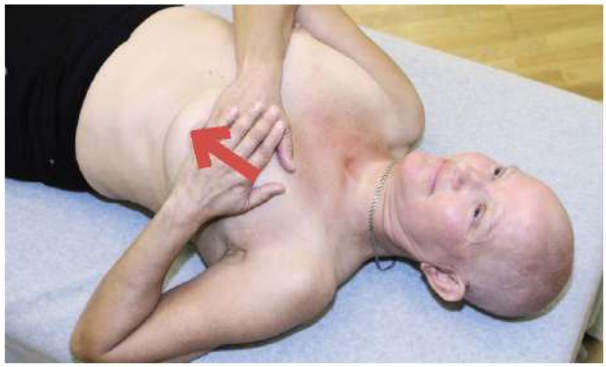
ØVELSE 1 · FORSKYDELIGHED

Her arbejder du med hele brystet for at bevare forskydeligheden og forebygge dannelse af arvæv. Øvelsen består af fem dele og tager cirka 10 minutter. Brug to-tre minutter på hver del. Slap af i arme og skuldre, mærk efter stramninger og varme.

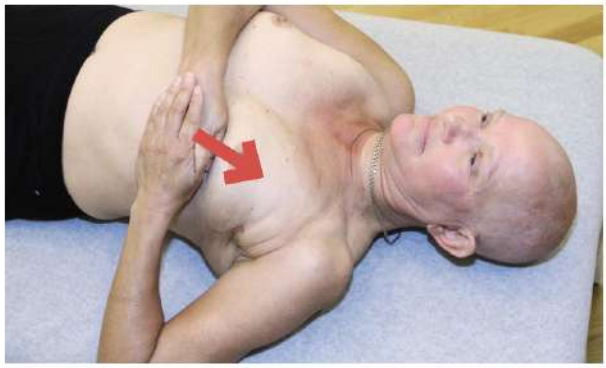
1. Placer din ikke-opererede sides hånd på den opererede side lige under kravebenet. Læg den anden hånd oven på, tryk let ned i vævet og lav en forskydning ned mod tæerne. Drej eventuelt hovedet væk fra den opererede side.



2. Flyt hænderne lidt længere ned, men stadig oven over brystvorten. Tryk let ned i vævet og lav en forskydning mod tæerne.

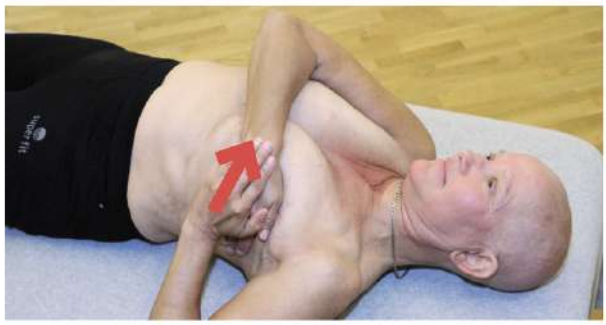


3. Flyt hænderne ned under brystet. Tryk let ned i vævet og lav en forskydning op mod næsen.

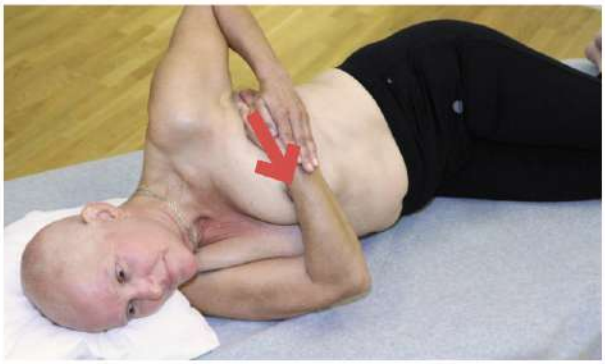


VÆVSBEHANDLING

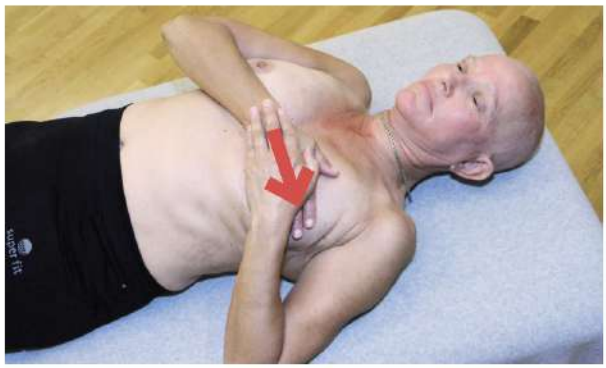
4 Flyt hænderne ud på siden af kroppen. Tryk ind i vævet og lav en forskydning ind mod brystbenet.



4a Du kan også lave øvelsen, hvor du ligger på din ikke-opererede side.



5 Flyt hænderne, så de ligger på brystbenet og udover det opererede bryst. Tryk ned i vævet og forskyd ud mod den opererede sides armhule.



Mærker du ingen stramning?

Selvom du ingen stramning mærker lige nu, er det vigtigt, at holde vævet så smidigt som muligt inden strålebehandlingen. Du vil ofte opleve, at selve strålebehandlingen vil gøre dit væv mere stramt.

Lav gerne en aftale med en fysioterapeut fire uger efter endt strålebehandling.

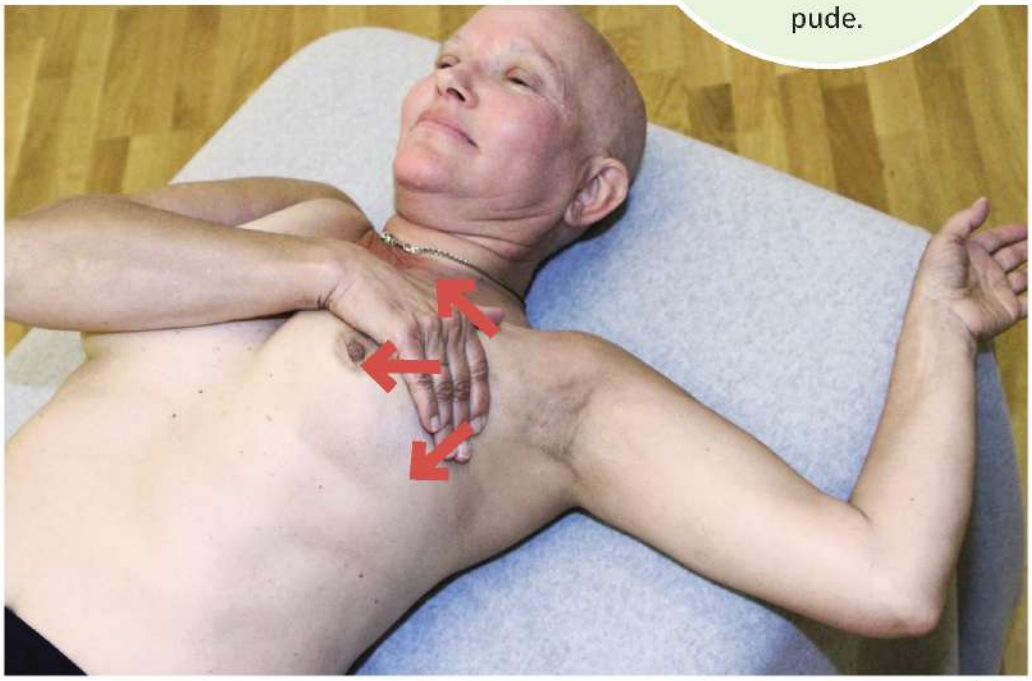
ØVELSE 2 · ARMHULEN

Her arbejder du med at smidiggøre det opererede område samt stramheden i din arm og armhule.

- Placer din hånd på dit opererede bryst. Tryk først let ned i vævet og lav derefter et træk væk fra den opererede armhule. Hånden må ikke glide på huden
- Vær opmærksom på, at din skulder er i underlaget
- Flyt hånden rundt og træk langsomt i forskellige retninger, indtil du finder det strammeste sted
- Hold denne stilling til stramningen slipper. Det kan tage flere minutter
- Gentag øvelsen, hvis der er flere stramme steder

OBS!

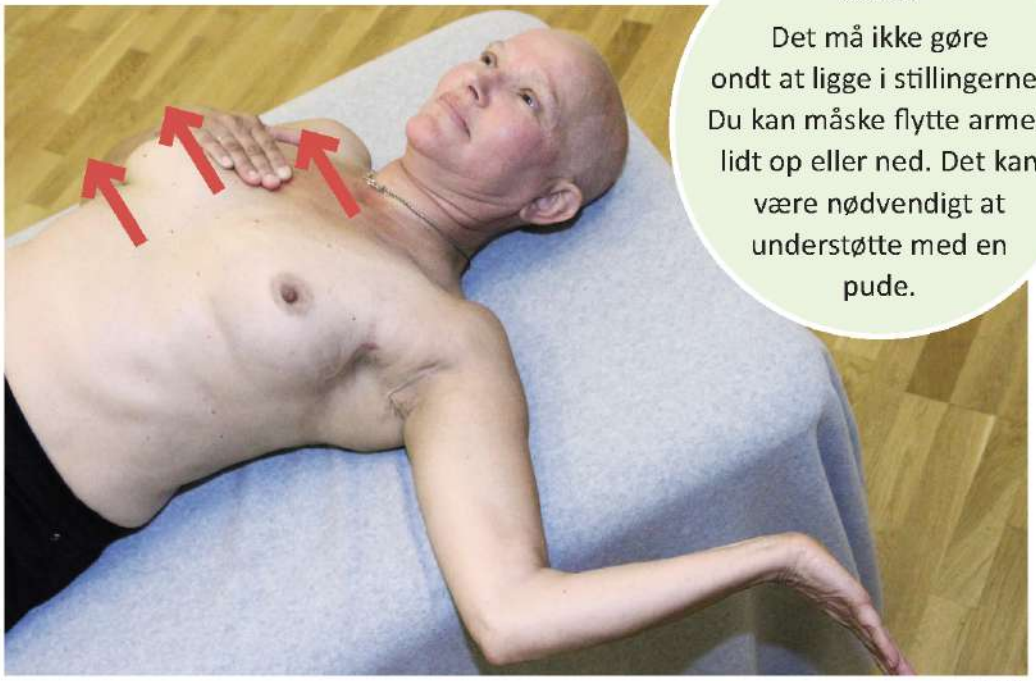
Det må ikke gøre ondt at ligge i stillingerne. Du kan måske flytte armen lidt op eller ned. Det kan være nødvendigt at understøtte med en pude.



ØVELSE 3 · NERVEVÆV

Her arbejder du med at smidiggøre det opererede område og med mobilisering af nervevævet. Du skal starte med at undersøge vævet for at finde det strammeste sted.

- Placer din hånd på dit ikke-opererede bryst, lige under kravebenet. Tryk først let ned i vævet og lav derefter et træk væk fra den opererede side. Hånden må ikke glide på huden
- Flyt derefter hånden ned på det ikke-opererede bryst og gentag samme forskydning.
- Gentag også under brystet
- Vælg det strammeste sted
- Hold denne stilling til stramningen slipper. Det kan tage flere minutter. Samtidig vipper du langsomt med det andet håndled for at mobilisere nervevævet. Vip 30 gange
- Vær opmærksom på, at din skulder er i underlaget
- Gentag øvelsen, hvis der er flere stramme steder



OBS!

Det må ikke gøre ondt at ligge i stillingerne. Du kan måske flytte armen lidt op eller ned. Det kan være nødvendigt at understøtte med en pude.

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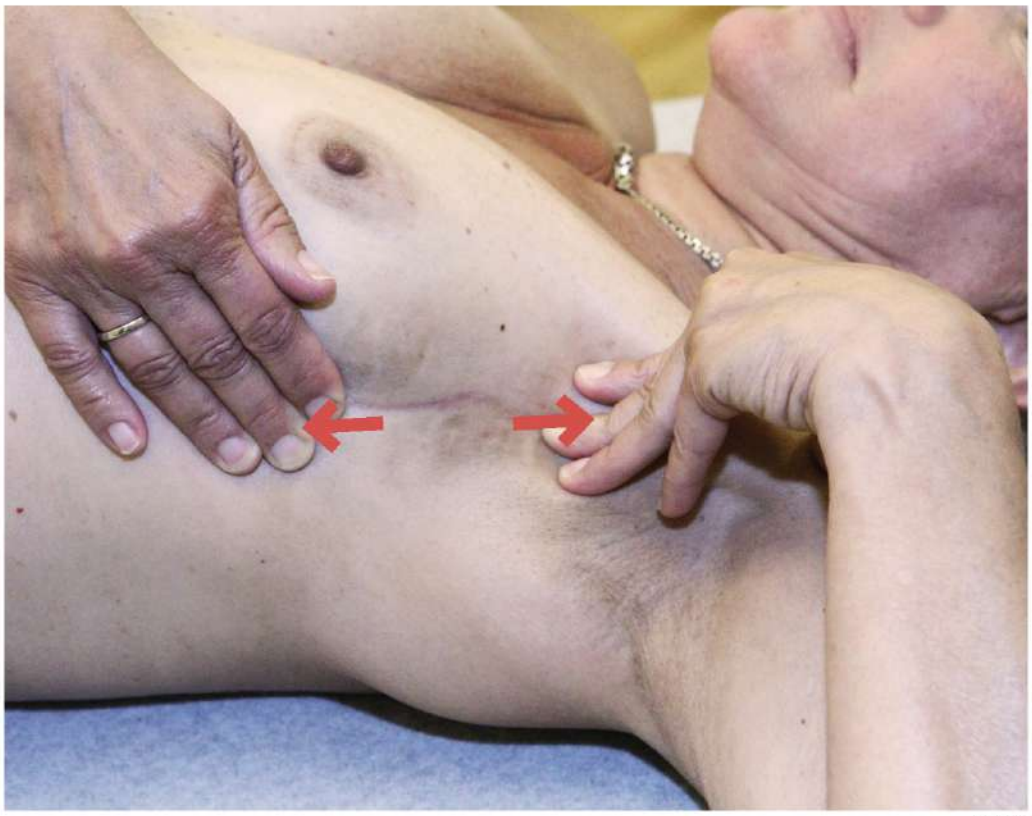
ØVELSE 4 · BEHANDLING AF SELVE ARRET

- Placer fingrene på arret med et par centimeters mellemrum og træk i arrets længderetning, indtil du mærker, at det strammer
- Slip igen, når du mærker, at stramningen aftager
- Gentag, indtil du har arbejdet arret igennem
- Du kan lave øvelsen foran et spejl, hvis du ikke kan mærke, hvor arret er



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TRÆNINGSØVELSER FOR AT ØGE BEVÆGELIGHEDEN

ØVELSE 5 · SIDESTRÆK

- Stå med let afstand mellem fødderne
- Tag fat om håndleddet på din opererede side
- Skyd hoften ud til den opererede side og før din arm skråt frem og op foran hovedet
- Mærk strækket på siden af kroppen

OBS!

I øvelserne 5-9 holdes stillingen i 30-45 sekunder, mens du har en rolig vejrtrækning. Øvelserne må gerne stramme, men ikke gøre ondt. Hverken undervejs eller bagefter.

ØVELSE 6 · STRÆK AF NAKKEMUSKULATUR

- Stå med let afstand mellem fødderne
- Træk hagen ind, drej hovedet væk fra den opererede side
- Bøj nakken, så næsen nærmer sig armhulen
- Placer den ikke-opererede sides hånd på baghovedet og lad den hvile tungt
- Mærk strækket på bagsiden af nakken på den opererede side

TRÆNINGSØVELSER FOR AT ØGE BEVÆGELIGHEDEN

ØVELSE 7 · UNIVERSALSTRÆK

- Lig på ryggen med den opererede sides arm liggende strakt ud til siden – eller med bøjet albue
- Før knæene væk fra den opererede side og lad dem hvile i underlaget eller på en pude
- Hold begge skuldre i underlaget
- Mærk strækket over brystkassen, i armhulen og ned over kroppen

ØVELSE 8 · LIGE STRÆK

- Stil dig foran et bord med god afstand mellem fødderne
- Læg håndfladerne på bordet og skub enden bagud. Undlad at knejse med nakken
- Du skal mærke strækket på forsiden af brystkassen og undersiden af armen

TRÆNINGSØVELSER FOR AT ØGE BEVÆGELIGHEDEN

ØVELSE 9 · STRÆK AF BRYSTMUSKULATUR

- Læg dig som på billedet med hænderne bag ved hovedet – eller på panden
- Pres langsomt albuerne ned mod gulvet
- Understøt eventuelt med en pude, så armen kan slappe af
- Du skal mærke strækket i brystmusklen

ØVELSE 10 · STRÆK AF ARMHULE OG FORSIDE

- Stil dig ved en væg
- Placer din opererede sides hånd på væggen. Armen skal være afslappet og underarmen skal hvile på væggen.
- Sæt den modsatte fod frem til væggen og bøj lige ned i knæene, til du mærker den første stramning på forsiden af brystkassen og/eller i armhulen

OBS!

I øvelserne 5-10 holdes stillingen i 30-45 sekunder, mens du har en rolig vejrtrækning. Øvelserne må gerne stramme, men ikke gøre ondt. Hverken undervejs eller bagefter.

ØVELSE 11 · SIDDENDE SELVSPÆNDING

- Sid på gulvet med strakte ben og armene placeret bag dig så tæt på kroppen som muligt. Fingrene skal pege væk fra dig selv
- Stem i gulvet med hænderne og skyd brystkassen langsomt frem og opad
- Hold hagen inde og skuldrene nede
- Hav en rolig og afslappet vejrtrækning og hold stillingen i ca 20 sekunder
- Gentag to-tre gange

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TRÆNINGSØVELSER FOR AT ØGE BEVÆGELIGHEDEN

OBS!

Øvelserne 12-14 udføres i et langsomt og kontrolleret tempo i op til 15 gentagelser. Hold derefter en kort pause og gentag igen. Dog højst 2 x 15 gentagelser.

ØVELSE 12 · BEVÆGELIGHED I SKULDEREN

- Placer hænderne på enden af en stav eller noget lignende.
- Stræk albuerne og før langsomt armene over hovedet, til du mærker den første stramning
- Kom langsomt tilbage til udgangsstillingen

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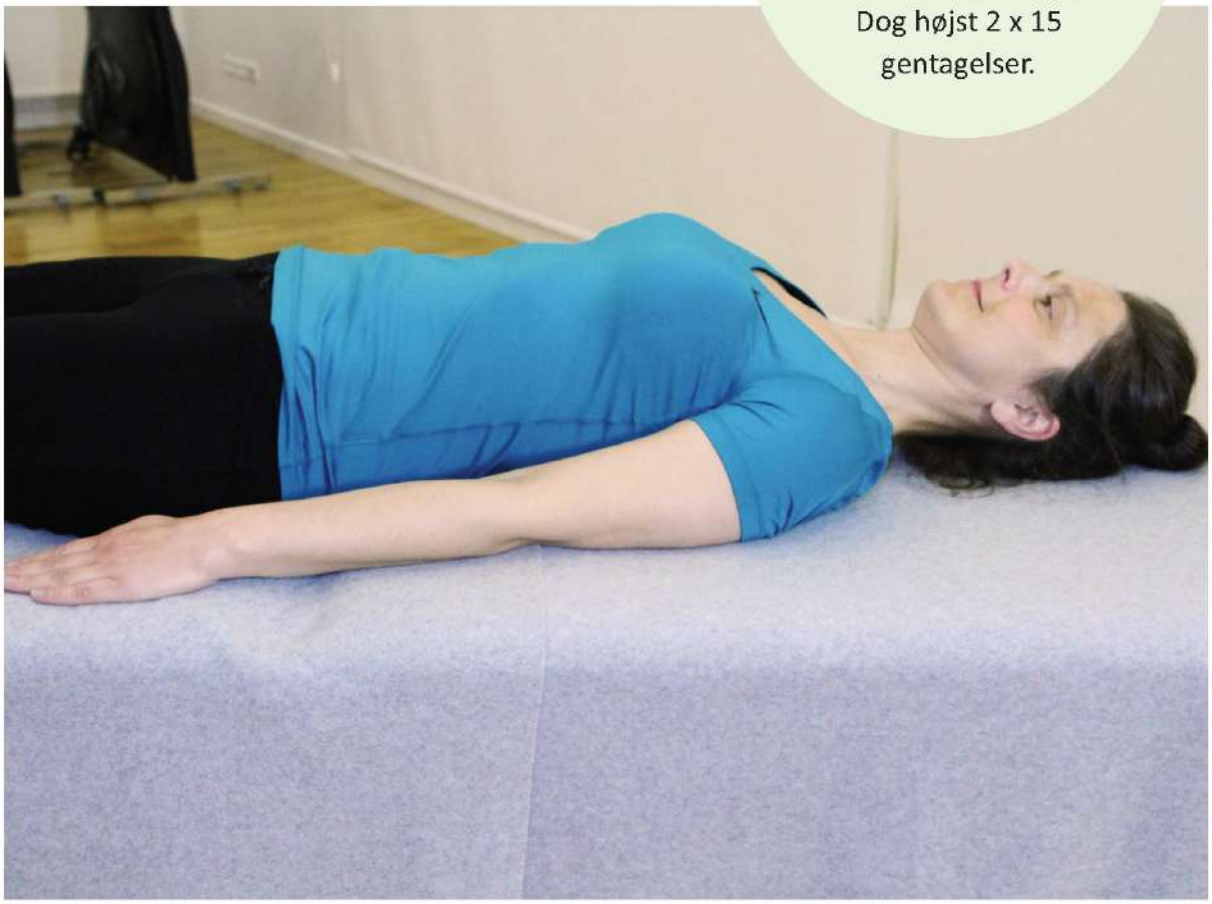
TRÆNINGSØVELSER FOR AT ØGE BEVÆGELIGHEDEN

ØVELSE 13 · LIGGENDE SELVSPÆNDINGSØVELSE

- Lig på ryggen med armene langs siden af kroppen
- Træk langsomt skuldrene ned mod underlaget og gør dig bredskuldret
- Forestil dig, at skulderbladene trækker sig ind mod rygsøjlen
- Undgå at løfte brystkassen
- Pres armene ned i underlaget
- Hold stillingen 10 sekunder og slip langsomt

OBS!

Øvelserne 12-14 udføres i et langsomt og kontrolleret tempo i op til 15 gentagelser. Hold derefter en kort pause og gentag igen. Dog højst 2 x 15 gentagelser.



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TRÆNINGSØVELSER FOR AT ØGE BEVÆGELIGHEDEN

ØVELSE 14 · TRÆNING AF BRYSTMUSKULATUR OG MUSKLER OMKRING SKULDERBLAD

- Stil dig cirka 30-40 cm fra væggen
- Placer dine hænder på væggen i skulderhøjde
- Bøj langsomt armene, så kroppen nærmer sig væggen og stræk dem langsomt igen
- Hold kroppen lige og undgå at stritte med enden
- Hold skuldrene nede under hele øvelsen

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ANBEFALINGER UNDER DIN STRÅLEBEHANDLING

Når du er i strålebehandling og i ugerne efter, skal du tage særlige hensyn til dit væv.

Du vil ofte opleve, at vævet bliver mere stramt i tiden under og efter din strålebehandling. Derfor er det vigtigt med daglige øvelser for at holde vævets smidighed ved lige.

Her anbefaler vi, at du har fokus på øvelse 3, hvor du arbejder på den ikke-opererede side og holder pause med de andre vævsøvelser. Dem kan du med fordel genoptage tre-fire uger efter afsluttet strålebehandling.

Hvis du styrketræner, er det også en god ide i samme periode at sætte mindre vægt på, når du træner overkrop og arme. Du kan udføre øvelserne 5-14 i pjecen gennem hele strålebehandlingen.

Det er en god ide, at få tilset dit væv af en fysioterapeut ca. fire uger efter endt strålebehandling.

bryst rehab.dk

Appendix C Participant Satisfaction Questionnaire for the BRECOR Program

Participant Satisfaction Survey

We would like to ask you about your experience in this study. Your experience is very important in helping us improve the program. Please answer each question as honestly as you can. Please answer using your first thoughts about each question. If there are questions you do not feel comfortable answering, you do not need to answer them.

For the following questions, please mark the most appropriate answer. If you have any additional points you would like to mention for each question, please do so.

---

1. How often have you performed your home-based rehabilitation program during the past 12 weeks?

Not at all	Once or twice	1 to 3 times per week	4 to 6 times per week	Daily
☐1	☐2	☐3	☐4	☐5

If never: Please tell us why you have not performed the home-based rehabilitation program:

_____

_____

2. How often have you logged onto the BRECOR website during the past 12 weeks?

Never	One or two times	Three to four times	Five to six times	More than six times
☐1	☐2	☐3	☐4	☐5

If never: Please tell us why you have not logged onto the BRECOR website:

_____

_____

3. Overall, how satisfied are you with the rehabilitation program supported by the website?

Very unsatisfied ☐1	Quite unsatisfied ☐2	Neutral ☐3	Quite satisfied ☐4	Very satisfied ☐5

Usability of website and technical issues

4. To what extent did you find the website easy to use and navigate?

Very difficult ☐1	Quite difficult ☐2	Neutral ☐3	Quite easy ☐4	Very easy ☐5

5. To what extent were the exercise videos easy to understand and follow?

Very difficult ☐1	Quite difficult ☐2	Neutral ☐3	Quite easy ☐4	Very easy ☐5

6. To what extent did you find the content of the rehabilitation videos appropriate?

Very inappropriate ☐1	Somewhat inappropriate ☐2	Neutral ☐3	Somewhat appropriate ☐4	Very appropriate ☐5

7. To what extent did you experience technical difficulties when you used the exercise videos?

Not at all ☐1	A little ☐2	Neutral ☐3	Quite alot ☐4	Very much ☐5

8. What digital equipment did you use to play the exercise videos?

PC/Computer ☐
Tablet ☐
Smartphone ☐
Other: _____

Please indicate how much you agree with the following statements:

9. I was ready to do my home-based program on my own after the baseline clinical assessment:

Completely disagree ☐1	Somewhat Disagree ☐2	Neutral ☐3	Somewhat Agree ☐4	Completely agree ☐5

10. I would have preferred more instruction before doing the home-based program:

Completely disagree ☐1	Somewhat Disagree ☐2	Neutral ☐3	Somewhat Agree ☐4	Completely agree ☐5

Use of website for rehabilitation

11. Overall, how much have you used the exercise videos to support your home-based rehabilitation program?

Not at all ☐1	A little ☐2	Neutral ☐3	Quite alot ☐4	Very much ☐5

12. To what extent did you do your home-based program *without* the support of the exercise videos?

Not at all ☐1	A little ☐2	Neutral ☐3	Quite alot ☐4	Very much ☐5

13. I used the exercise videos *a few times* until I was familiar with the exercises

Completely disagree ☐1	Disagree ☐2	Neutral ☐3	Agree ☐4	Completely agree ☐5

14. I used the exercise videos to support *most* of my home-based rehabilitation

Completely disagree ☐1	Disagree ☐2	Neutral ☐3	Agree ☐4	Completely agree ☐5

Barriers for use:

15. Please mark what potential barriers you have experienced with the home-based rehabilitation program:

a) The program was boring ☐
b) I was lonely while doing my home-based program ☐
c) I missed support from other women while doing the home-based program ☐
d) The home-based program was too time-consuming ☐
e) The home-based program was too difficult to access through the website ☐
f) It was inconvenient to do the home-based program ☐
g) No barriers ☐

Please indicate if you have encountered any other barriers for doing your home-based program:

_____

_____

_____

Use of website for non-rehabilitation

16. To what extent have you used the material on the BRECOR website about lymphedema?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

17. To what extent have you used the rest of the material on the BRECOR website (e.g., stories from other women with breast cancer, resources on mindfulness)

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

Use of other material (education pamphlet, logbook)

18. To what extent did you use the education pamphlet to support your home-based rehabilitation program?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

19. How often did you record your home-based rehabilitation in the logbook?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

20. To what extent has the use of the logbook increased your motivation to do the home-based program?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

21. To what extent did you do your home-based program *without* recording it on the logbook?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

Benefit

22. To what extent have you performed the home-based exercises more often than you would have without the support from the BRECOR website?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

23. To what extent has the BRECOR website and exercise videos improved your ability to perform your home-based rehabilitation exercises correctly?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

24. To what extent do you feel you benefitted from doing your home-based rehabilitation program?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

25. To what extent do you feel you benefitted from using the website to support your home-based rehabilitation?

Not at all	A little	Neutral	Quite alot	Very much
☐1	☐2	☐3	☐4	☐5

Please let us know if you have any other comments:

_____
_____
_____
_____

Thank you for participating in the BRECOR study.

Appendix D Motivation Questionnaire for the BRECOR Program

Intention, Attitude and Subjective Norm Questionnaire

This form contains questions about your thoughts and behaviour. Please answer each question as honestly as you can. No one will see your answers except for the study staff. Your answers will be kept secret and will never be put with your name in a report. Please answer using your first thoughts about each question. Do not go back later to "figure out" answers. Your answers will help us to understand the thoughts and behaviour of other women who are like you.

The home-based rehabilitation exercises reflect the arm exercises that your physical therapist has advised you to do at home using the website and education pamphlet. Please choose only one answer and try to complete all questions.

Pl.1. I have a plan for *where* to do home-based rehabilitation exercises as recommended by the physiotherapist during the next 12 weeks

1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

Pl.2. I have a plan for *which* home-based rehabilitation exercises to do during the next 12 weeks

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

Pl.3. I have a plan for *when* to do home-based rehabilitation exercises as recommended by the physiotherapist during the next 12 weeks

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

Pl.4. I have a plan for *how* to do home-based rehabilitation exercises as recommended by the physiotherapist during the next 12 weeks

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

I.1. I intend to do home-based rehabilitation exercises as recommended during the next 12 weeks

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

I.2. How motivated are you to do home-based rehabilitation exercises as recommended during the next 12 weeks?

☐	☐	☐	☐	☐	☐	☐
extremely unmotivated	quite unmotivated	slightly unmotivated	neutral	slightly motivated	quite motivated	extremely motivated

I think that for me to do home-based rehabilitation exercises during the next 12 weeks would be:

I.At.1.

☐	☐	☐	☐	☐	☐	☐
extremely useful	quite useful	slightly useful	neutral	slightly useless	quite useless	extremely useless

I.At.2.

☐	☐	☐	☐	☐	☐	☐
extremely beneficial	quite beneficial	slightly beneficial	neutral	slightly harmful	quite harmful	extremely harmful

I.At.3.

☐	☐	☐	☐	☐	☐	☐
extremely important	quite important	slightly important	neutral	slightly unimportant	quite unimportant	extremely unimportant

A.At.1.

☐	☐	☐	☐	☐	☐	☐
extremely enjoyable	quite enjoyable	slightly enjoyable	neutral	slightly unpleasant	quite unpleasant	extremely unpleasant

A.At.2.

☐	☐	☐	☐	☐	☐	☐
extremely pleasurable	quite pleasurable	slightly pleasurable	neutral	slightly painful	quite painful	extremely painful

A.At.3.

☐	☐	☐	☐	☐	☐	☐
extremely fun	quite fun	slightly fun	neutral	slightly boring	quite boring	extremely boring

I think that if I do home-based rehabilitation exercises during the next 12 weeks, most people who are important to me would be:

Sn.1.

☐	☐	☐	☐	☐	☐	☐
extremely disapproving	quite disapproving	slightly disapproving	neutral	slightly approving	quite approving	extremely approving

Sn.2.

☐	☐	☐	☐	☐	☐	☐
extremely discouraging	quite discouraging	slightly discouraging	neutral	slightly encouraging	quite encouraging	extremely encouraging

Sn.3.

☐	☐	☐	☐	☐	☐	☐
extremely unsupportive	quite unsupportive	slightly unsupportive	neutral	slightly supportive	quite supportive	extremely supportive

P.Bc.1. I have complete control over how often I will do home-based rehabilitation exercises during the next 12 weeks?

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

P.Bc.2. I have complete control over whether or not I do home-based rehabilitation exercises as recommended during the next 12 weeks?

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

Se.1. I am confident that I can do the home-based rehabilitation exercises as recommended during the next 12 weeks?

☐	☐	☐	☐	☐	☐	☐
not at all confident	quite unconfident	slightly unconfident	neutral	slightly confident	quite confident	extremely confident

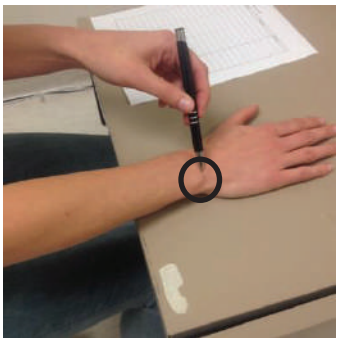
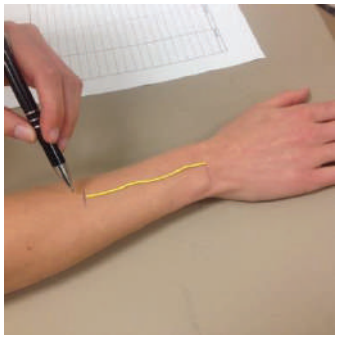
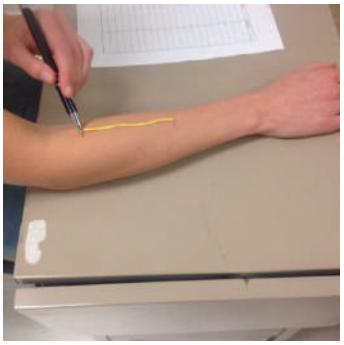
Se.2. I trust that I can do the home-based rehabilitation exercises as recommended during the next 12 weeks?

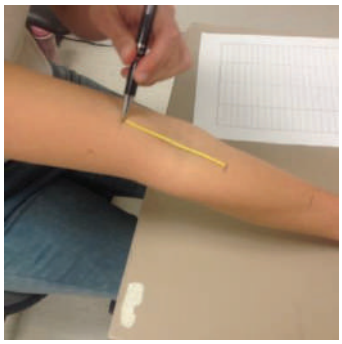
☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

Appendix E Instruction in Self-Measurement

<table>
<tr><th colspan="3">Instructions for marking and measuring arm circumference</th></tr>
<tr><td>What you will need</td><td colspan="2">1. A tape measure
2. A chair and table
3. A pen
4. A 10 cm long measurement stick</td></tr>
<tr><td colspan="3">Marking of five points on your arms
1. Start by sitting at a table with your arm in front of you. Rest your arm on the table with your palm facing down.
2. Use a pen to mark the following five points on your arm.</td></tr>
<tr><td>Where to start</td><td>a. Your wrist
On the back of your wrist you will feel a <u>bony landmark</u> on the outer side. Mark a line with the pen below this – closer to your fingers.

b. 2nd point
Place the measurement stick on your arm towards your shoulder at the wrist line. Mark a line with a pen.

c. 3rd point
Place the measurement stick on your arm towards your shoulder at the 10cm line. Mark a line with a pen.</td><td>a) 
b) 
c)  </td></tr>
</table>

	d. *4th point* Place the measurement stick on your arm towards your shoulder at the 20cm line. Extend your elbow. Mark a line with a pen. *e.* *5th point* Place the measurement stick on your arm towards your shoulder at the 30cm line. Mark a line with a pen.	d)  e) 
3.	Now use the pen to mark the same points on your other arm.	
4.	Once you have marked these **5 lines on both your arms** then you're ready to start measuring.	

After reading the instructions for use of the tape measure below, then please perform arm circumference measures at the 5 points on **both your arms**.

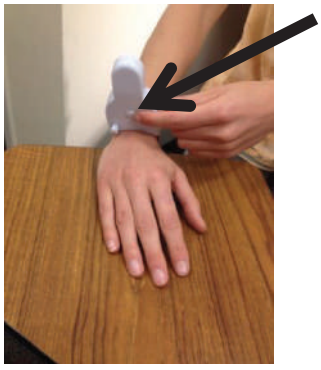
Instructions for use of the tape measure

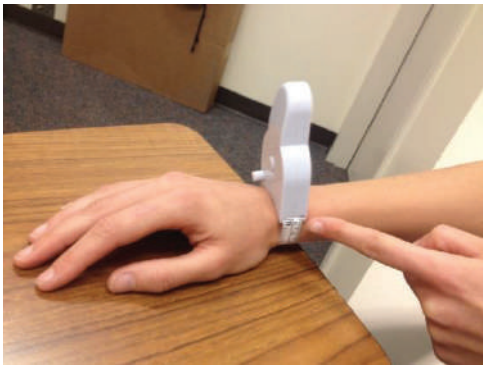
1. Draw the retractable tape out of the case
2. Fit the plastic peg attached to the end of the tape into the hole on the case
3. Encircle your arm at the level of measurement below the mark
4. Press the button on the case to automatically cinch the tape snugly around your arm.
5. Record your measurement reading in cm, at the point where the tape comes out of the case slot.

Note: the measurements on the outside of the tape measure do not start at zero. This is because the measurement includes the curved portion of the top of the case that fits against the arm.

For measures of your **right** arm:

- The button on the case of the tape measure should point towards your fingers.
- The reading is on the inside of your wrist/arm





For measures of your **left** arm:

- The button on the case of the tape measure should point towards your shoulder.
- The reading is on the inside of your wrist/arm

When you are familiar with the tape measure then you can start the measurements.

Instructions for the arm measurements

Arm measurements	1. Start with your non-dominant arm. 2. Rest your hand on the edge of the table with your palm facing down, and your wrist and arm unsupported by the table. Try to relax in the arm you are measuring. 3. Use the tape measure to measure the distance around your wrist just below the mark. Please double check your measurement prior to recording it. Record your measurement on the form provided, being careful to write it in the correct position corresponding to the non-dominant arm. 4. Continue measuring the circumference at 2nd, 3rd, 4th, and 5th mark. 5. Repeat steps 2-4 to measure your dominant arm.
Important points to remember	• All measurements are in cm and mm • When recording your measurements on the form provided, please double check that the measurements for your right arm are recorded on the space for the right arm on the form and similarly for the left arm.

Self-measured arm circumference at home

Study ID_____

Date _____

Were the self-measures difficult to perform (Please choose a number):

1 2 3 4 5 6 7 8 9 10

Very difficult Very easy

Appendix F Quiz on the Self-Measurement Technique

SELF-MEASURED ARM CIRCUMFERENCE STUDY

Short Self-assessment Quiz about the self-measurement technique.

STUDY ID: _____ DATE: _____

1. Have you read the instruction sheet? **Yes** No

2. Have you practiced using the tape, specifically how to hold the tape so that the reading in centimeters is on the inside of your arm? **Yes** No

3. Have you identified the bony landmark on the outside of your wrist? **Yes** No

4. Have you noticed that when measuring your right arm, the button on the case of the tape measure should point towards your fingers **Yes** No

5. Have you received and viewed the measurement video guide? **Yes** No

6. Have you noticed that when measuring your left arm, the button on the case of the tape measure should point towards your shoulder? **Yes** No

7. Have you practiced measuring your arm without recording it on the form? **Yes** No

8. Is your assessment at UBC scheduled within the next 2 days? **Yes** No

9. If you have lymphedema, have you remembered to remove your compression sleeve for 2 hours before doing the measurements? **Yes** No

8. Have you done any vigorous activity with your upper body within the last 48 hours (i.e. weight lifting or swimming)? Yes **No**

If you have circled the **bold** answers to all of the questions above, then you are ready to perform the self-measures and record these on the form.

If you have circled any non-bold answers, please take the time to review the study documents again and re-assess if you can now circle the bold answer. If you have any questions, please call the study coordinator Bolette Rafn.

We look forward to seeing you within the next two days.

Appendix G Thoughts and Beliefs Questionnaire for Self-Measurement

Self-measurement study
Women without BCRL

Thoughts and Beliefs Questionnaire

This form contains questions about your thoughts and beliefs about doing self-measurements of your arms. Please answer each question as honestly as you can. No one will see your answers except for the study staff. Your answers will be kept secret and will never be put with your name in a report. Please answer using your first thoughts about each question. Please do not go back later to "figure out" answers. Your answers will help us to understand the thoughts and beliefs of other women who are like you. Please choose only one answer and try to complete all questions.

The term "self-measures" used here means the five arm circumference measures that you have done on both your arms with support from the video guide and the written material.

Please indicate the extent of which you agree with the following statements:

1. I am motivated to do the self-measures of my arms at home every three months

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

2. I intend to do the self-measures of my arms at home every three months

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

3. I have a plan for how I will do the self-measures of my arms at home every three months

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

4. I think that for me to do the self-measures of my arms at home every three months would be:

☐	☐	☐	☐	☐	☐	☐
extremely unhelpful	quite unhelpful	slightly unhelpful	neutral	slightly helpful	quite helpful	extremely helpful

5. I think that for me to do the self-measures of my arms at home every three months would be:

☐	☐	☐	☐	☐	☐	☐
extremely unimportant	quite unimportant	slightly unimportant	neutral	slightly important	quite important	extremely important

6. I think that if I do the self-measures of my arms at home every three months, most people who are important to me would be:

☐	☐	☐	☐	☐	☐	☐
extremely unsupportive	quite unsupportive	slightly unsupportive	neutral	slightly supportive	quite supportive	extremely supportive

7. I have complete control over whether or not I do the self-measures of my arms at home every three months

☐	☐	☐	☐	☐	☐	☐
strongly disagree	disagree	slightly disagree	neutral	slightly agree	agree	strongly agree

8. How confident are you that you can do self-measures of your arms at home every three months?

☐	☐	☐	☐	☐	☐	☐
not at all confident	quite unconfident	slightly unconfident	neutral	slightly confident	quite confident	extremely confident

---

The next set of questions will ask you specifically about your thoughts about getting lymphedema. Please indicate the extent of which you agree with the following statements:

9. I believe that lymphedema is a serious condition

☐	☐	☐	☐	☐
Not at all	Somewhat	Neutral	Quite a bit	Very much

10. I feel that getting lymphedema would interfere with my life

☐	☐	☐	☐	☐
Not at all	Somewhat	Neutral	Quite a bit	Very much

11. How likely do you think it is that, at some point in your life, you will get lymphedema?

☐	☐	☐	☐	☐
Not at all	Somewhat likely	Neutral	Quite likely	Very likely

12. I am worried about getting lymphedema

☐	☐	☐	☐	☐
Not at all	Somewhat	Neutral	Quite a bit	Very much

13. I am able to calm myself when anxious or worried about getting lymphedema

☐	☐	☐	☐	☐
Not at all	Somewhat	Neutral	Quite a bit	Very much

14. I think that doing self-measures of my arms at home every three months will increase my worry about getting lymphedema

☐	☐	☐	☐	☐
Not at all	Somewhat	Neutral	Quite a bit	Very much

Thank you for completing this questionnaire.

Appendix H Instructions for Self-Assessment of Shoulder ROM

The following two tests will help to identify any limitations in your shoulder range of motion following your surgery for breast cancer.

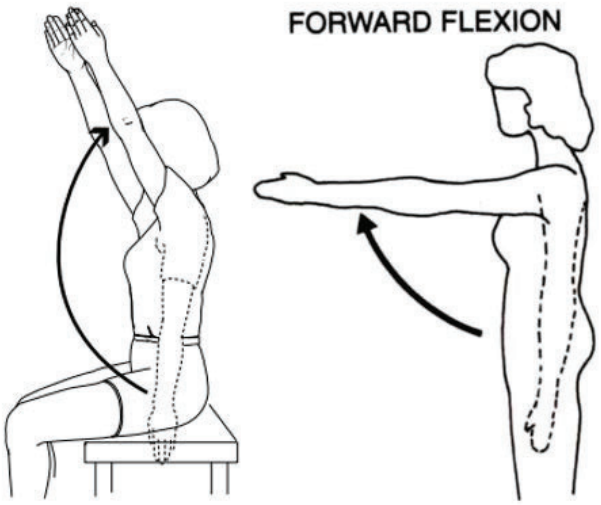
Testing position: For both tests, please stand or sit in front of a mirror so you can see if there is any difference in range of motion between your surgery and non-surgery side.

When to test: Please do these tests at your post-surgery physiotherapy visit at Surrey Memorial Hospital.

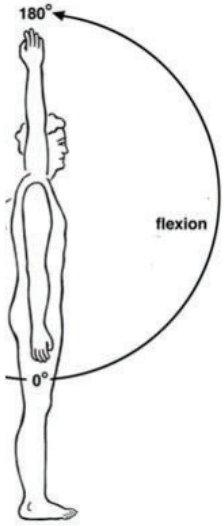
1) Shoulder forward flexion

To assess your shoulder flexion range of motion, please and move both your arms forward at the same time *as high as they go*.

Figure 1: Forward flexion – forward movement



End position:
Arms along your head

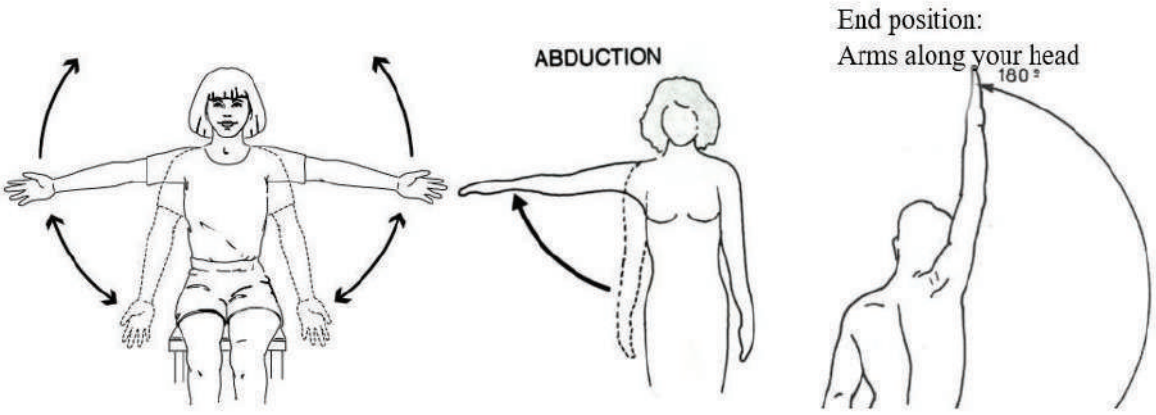


Is your shoulder flexion reduced on your surgery side compared to your non-surgery side?	Was the movement painful on your surgery side?
Yes ☐ No ☐	Yes ☐ No ☐

2) Shoulder abduction

To assess your shoulder abduction range of motion, please move both your arms sideways at the same time *as high as they go*.

Figure 2: Abduction – sideways movement



Is your shoulder abduction reduced on your surgery side compared to your non-surgery side? Yes ☐ No ☐	Was the movement painful on your surgery side? Yes ☐ No ☐

Thank you for completing the tests!

Appendix I Physical Therapist-Assessment of Shoulder ROM

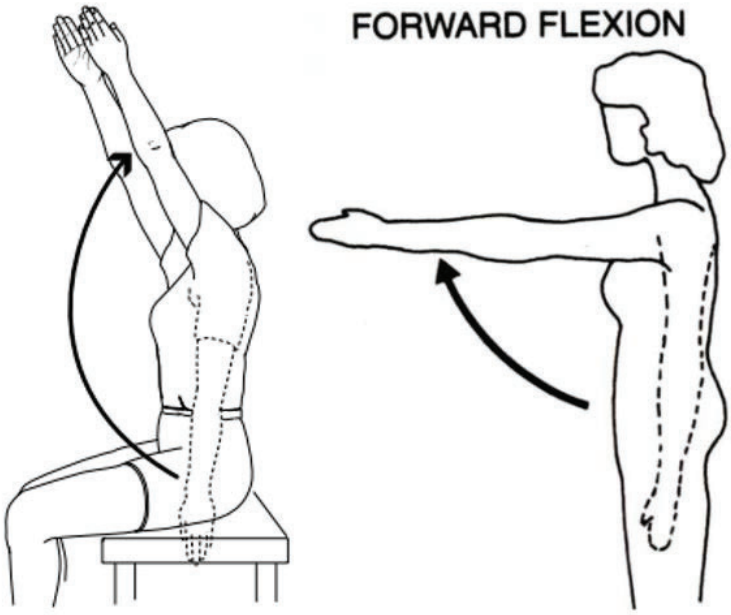
Testing position: Have the patient sit or stand in front of you.

When to test: At the early post-surgery physiotherapy visit (one to three months post breast cancer surgery).

1) **Shoulder forward flexion**

Ask the patient to do active shoulder flexion on both sides at the same time until end range.

Figure 1: Forward flexion



Is the patient's active shoulder flexion reduced on the surgery side compared to the non-surgery side?

Yes ☐ No ☐

If yes, please measure the flexion ROM and record it here

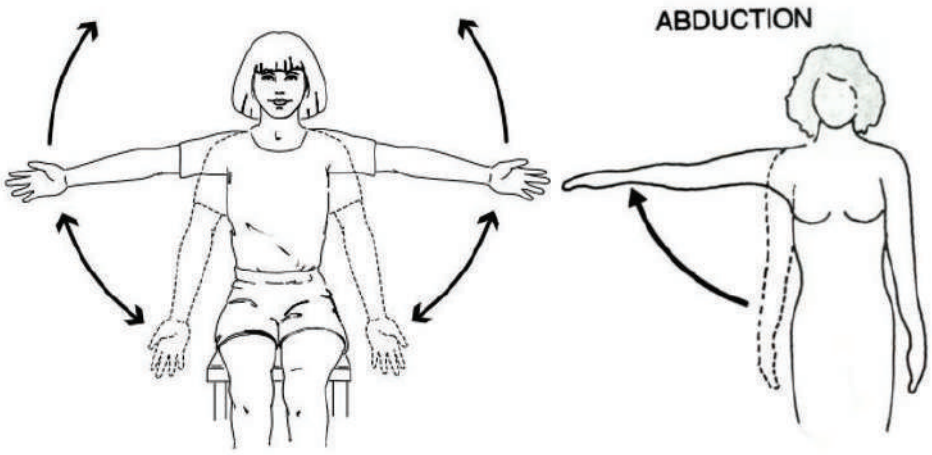
Left_____degrees Right_____degrees

Surgery side Left ☐ Right ☐

1) Shoulder abduction

Ask the patient to do active shoulder abduction on both sides at the same time until end range.

Figure 2: Abduction



Is the patient's active shoulder abduction reduced on the surgery side compared to the non-surgery side?

Yes ☐ No ☐

If yes, please measure the abduction ROM and record it here
Left_____degrees Right_____degrees

Surgery side Left ☐ Right ☐

Appendix J Rehabilitation Services and Needs Questionnaire

Rehabilitation services and needs

Study ID: _____ Date: _____

1. Did you have measures taken of shoulder range of motion before your surgery?
Yes____ No____

If yes, who performed the measures?

- ☐ Myself
- ☐ Surgeon/surgical oncologist
- ☐ Plastic surgeon
- ☐ Physiotherapist
- ☐ Chiropractor
- ☐ Other (please specify) _____

2. Did you have measures taken of arm circumference before your surgery?
Yes____ No____

If yes, who performed the measures?

- ☐ Myself
- ☐ Surgeon/surgical oncologist
- ☐ Plastic surgeon
- ☐ Physiotherapist
- ☐ Chiropractor
- ☐ Other (please specify)_____

3. When did you receive education relative to upper-body rehabilitation?

☐ Never

☐ Before breast cancer surgery

☐ Within the first month after surgery

☐ Later (please specify when)_____

4. Who gave you upper-body education relative to your breast cancer?
No one____ Surgeon/surgical oncologist____ Plastic surgeon____ Physiotherapist____
Chiropractor____ Other health care professional_____ (please specify)

5. Were you referred to physiotherapy during treatment?
Yes____ No____

6. If yes, who referred you to physiotherapy?
Myself____
Surgeon/surgical oncologist____ Plastic surgeon____ Other health care professional (please specify) _____ Not applicable: ____

If referred, what did you see a physiotherapist for?

Shoulder mobility:	Yes____	No____
Upper-body muscle strengthening:	Yes____	No____
Lymphedema:	Yes____	No____
General fitness/endurance:	Yes____	No____
Other problems associated with breast cancer:	Yes____	No____

Please specify:_____

If referred, did you see a physiotherapist:

☐ At a private practice

☐ At a public facility (i.e. hospital)

☐ Both privately and publicly

7. Did you self-manage (self-treat) any upper-body issues *during* treatment?
Yes____ No____
Example of self-management/treatment: This could be performing rehabilitation exercises for your upper-body at home (stretching or strengthening), or performing scar tissue massage on yourself.

8. Did you self-manage (self-treat) any upper-body issues *after* treatment?
Yes____ No____

9. If you did self-management, did you have sufficient support to do so?
Yes____ No____ Not applicable: ____
Comments:_____

10. Did you use alternative or complementary treatment (i.e. mindfulness, natural products, massage, special diet, meditation)
Yes____ No____
Comments:_____

11. Did you experience any of the following upper-body issues one or more years after completing treatment?

Pain:	Yes____	No____
Numbness:	Yes____	No____
Tightness:	Yes____	No____
Decreased shoulder range of motion:	Yes____	No____
Decreased muscle strength:	Yes____	No____
Cording:	Yes____	No____
Limitations in performing daily activities	Yes____	No____
Skin changes (fibrosis/scaring):	Yes____	No____
Lymphedema:	Yes____	No____
Skin infection/cellulitis:	Yes____	No____

12. Do you <u>currently</u> experience any of the following upper-body issues?

Pain:	Yes____	No____
Numbness:	Yes____	No____
Tightness:	Yes____	No____
Decreased shoulder range of motion:	Yes____	No____
Decreased muscle strength:	Yes____	No____
Cording:	Yes____	No____
Limitations in performing daily activities	Yes____	No____
Skin changes (fibrosis/scaring):	Yes____	No____
Lymphedema:	Yes____	No____
Skin infection/cellulitis:	Yes____	No____

Appendix K Focus Group Guides

Focus group guide for women with breast cancer

Introduction

Good-morning/afternoon. Thank you for taking the time to attend this focus group. We are very appreciative of your openness and generosity to share your experiences with us. The information that you share with us today will help us better understand and aid us in our efforts to ensure that future rehabilitation programs and services address the needs and unique challenges experienced by women who have been diagnosed with breast cancer.

You've been invited to share your story because you have undergone treatment for breast cancer. We know that women with breast cancer experience upper-body issues during and after treatment that may impact normal activities, cause physical changes and impact other aspects of your social life. So, today we'll ask you to tell us about your experiences with upper-body rehabilitation and your perspective on performing surveillance for upper-body issues on yourself. We'll also ask about your thoughts on programs to help you and other women diagnosed with breast cancer detect and manage these issues yourselves. Particularly, we're looking forward to hearing about your personal experience with breast cancer rehabilitation in relation to the services you received and upper-body issues that you may have experienced.

The idea of this focus group is to allow you to share your views in an informal setting. There is no right or wrong answers and you should not strive for consensus. The things you share in this focus group are confidential and I therefore ask you to respect the privacy of others and not discuss this conversation outside of the focus group. Your participation is voluntary and you have the right not to answer the questions and to leave this focus group at any time. As discussed in the consent form and following your permission, this discussion will be audio- and video-recorded in order not to miss any of your comments. I should point out again that anything you say today will be kept confidential and we'll remove any identifying information so you remain anonymous in any reports, publications, or presentations we make. We therefore use pseudonym names in this focus group. I foresee today's focus group will last approximately 60 minutes.

The last point I'd like to make is that even though I'll be asking questions from a focus group guide to make sure I ask the same set of questions to all women I meet, if there is additional information on this topic that you want to share that I don't ask about, feel free to do so.

Strengths and weaknesses of current rehabilitation services

- Can you describe the experiences you have had with the rehabilitation services you received before/after the surgery for breast cancer?
    - Can you describe what made the experiences positive/negative?
- To what extent would you have liked to receive other/more services?
- To what extent were the services you received sufficient to meet your needs and concerns regarding the development of upper-body issues?
- Can you describe the services you have received in relation to prevention and detection of lymphedema?
- To what extent were those services sufficient to meet your concerns regarding developing lymphedema?

Motivation and barriers

- What motivates you to do rehabilitation exercises for your upper-body?
- What barriers have you experienced in performing rehabilitation exercises for your upper-body?
- In what context do you prefer to do rehabilitation (i.e. home, sports center, hospital, community center)?

Self-management

- Can you describe the advantages and disadvantages for you to perform upper-body rehabilitation at home?
- What resources would you need to be comfortable in performing upper-body rehabilitation exercises at home?

- Can you describe the advantages and disadvantages for you to perform surveillance for lymphedema on yourself? (i.e. measure your arm circumference every three months)
- What resources would you need to be comfortable in performing arm circumference measures regularly at home?
- Can you describe the advantages and disadvantages for you to use technology (website and/or smartphone application) to support surveillance and rehabilitation after surgery for breast cancer?

Definition of upper-body issues

- What components do you think are relevant when defining upper-body issues? (i.e. objective measures like shoulder range of motion, muscle strength and self-reported outcomes like pain, and ability to perform everyday activities)
- How would you define breast cancer-related upper-body issues?

Focus group guide for rehabilitation professionals

Introduction

Good-morning/afternoon. Thank you for taking the time to attend this focus group. We are very appreciative of your openness and generosity to share your experiences with us. The information that you share with us today will help us better understand and aid us in our efforts to ensure that future rehabilitation programs and services address the needs and unique challenges experienced by women who have been diagnosed with breast cancer.

You've been invited to attend this focus group because you have experience in working with rehabilitation of upper-body issues among women who have undergone treatment for breast cancer. As you may know, many women with breast cancer experience chronic upper-body issues after treatment that may impact normal activities, cause physical changes and impact other aspects of their social life. So, today we'll ask you to tell us about your experiences with upper-body rehabilitation at your workplace and your perspective on recommending self-managed surveillance for upper-body issues. We'll also ask about your thoughts on programs to support women diagnosed with breast cancer to detect and manage these issues with the support from relevant health professionals.

The idea of this focus group is to allow you to share your views in an informal setting. There is no right or wrong answers and you should not strive for consensus. The things you share in this focus group are confidential and I therefore ask you to respect the privacy of others and not discuss this conversation outside of the focus group. Your participation is voluntary and you have the right not to answer the questions and to leave this focus group at any time. As discussed in the consent form and following your permission, this discussion will be audio- and video-recorded in order not to miss any of your comments. I should point out again that anything you say today will be kept confidential and we'll remove any identifying information so you remain anonymous in any reports, publications, or presentations we make. We therefore use pseudonym names in this focus group. I foresee today's focus group will last approximately 60 minutes.

The last point I'd like to make is that even though I'll be asking questions from a focus group guide to make sure I ask the same set of questions to all therapists I meet, if there is additional information on this topic that you want to share that I don't ask about, feel free to do so.

Strengths and weaknesses of current rehabilitation services

- Can you describe the strengths and weaknesses of the upper-body rehabilitation services that your workplace provides for women with breast cancer?
- Can you describe the strengths and weaknesses of the lymphedema services that your workplace provides?

Self-management: *upper-body rehabilitation*

- Can you describe what you think about self-managed rehabilitation?
- Can you describe what you think about using technology to support women with breast cancer in self-managed rehabilitation?
- What are the advantages and disadvantages of women with breast cancer performing upper-body rehabilitation at home?
- What resources would you need to be comfortable in recommending self-managed upper-body rehabilitation?
- What potential impact may a self-management rehabilitation program have on your job?

Self-management: *surveillance for lymphedema*

- What are the advantages and disadvantages of women with breast cancer performing self-surveillance for lymphedema? (i.e. measure their own arm circumference every three months)
- What resources would you need to be comfortable in recommending self-surveillance for lymphedema?
- What potential impact may a self-management surveillance program for lymphedema have on your job?

Definition of upper-body issues

- To what extend do you think there exists a clear definition of breast cancer-related upper-body issues?
- Do you currently use an explicit definition of upper-body issues when making treatment plans and evaluating outcomes?
- What components do you think should be included in a definition of upper-body issues? (i.e. objective measures like shoulder range of motion, muscle strength and patient-reported outcomes like pain, function and participation)
- What are your thoughts about using pre-surgery vs. non-affected side as comparison to define upper-body issues?
- How would you define breast cancer-related upper-body issues?