Recommendations for implementation of exercise for patients with metastasized breast cancer

based on their exercise preferences, knowledge and attitudes, beliefs, and perceived barriers and facilitators

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PREFERABLE

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DELIVERABLE 3.3 of the PREFERABLE project

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Conflicts of interest

The authors declare no conflicts of interest.

Disclaimer

The information in this document is based on Deliverable 3.3, '*Recommendations related to exercise preferences, knowledge and attitudes, beliefs, barriers and facilitators of patients with MBC*' of the EU funded project (No. 825677). The information is provided as is and no guarantee or warranty is given that the information is fit for any particular purpose. The user thereof uses the information at its sole risk and liability. The opinions expressed in the document are of the authors only and in no way reflect the European Commission's opinions.

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1 PERSPECTIVE recommendations

1.1 Introduction

Exercise has shown to be effective to reduce many side effects, including fatigue, for people during or after cancer treatment with intent to cure. The evidence regarding the effectiveness for people with advanced stages of cancer was inconclusive. The PREFERABLE project aimed to strengthen the evidence base in this clinical context, through conducting a full-scale randomized controlled trial of exercise for people with metastasized breast cancer (MBC) to reduce fatigue and improve quality of life (EFFECT) and by conducting a social sciences study to explore the perspective of patients with MBC about their perceived barriers, facilitators, values and outcome expectations (PERSPECTIVE).

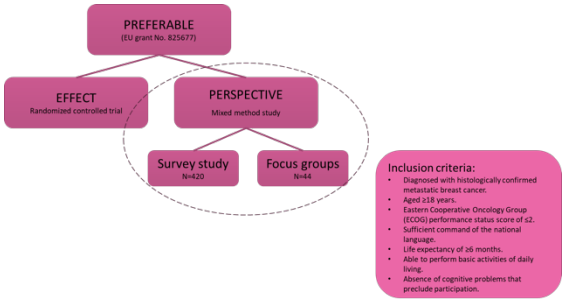

Figure 1: The two sub studies of PREFERABLE and inclusion criteria for PERSPECTIVE

The results of the PERSPECTIVE study are intended to support implementation of exercise as part of cancer care for people with MBC, if the EFFECT study demonstrates such an intervention is effective.

To this end, PERSPECTIVE consisted of a survey including 420 MBC patients from five EU countries: Poland, Sweden, Germany, Spain, and the Netherlands; and focus groups including 44 MBC patients from four EU countries: Poland, Sweden, Germany, and Spain. Previous focus groups had been conducted in the Netherlands[1] and the results of that study are also taken into consideration here.

The results of the PERSPECTIVE studies were discussed in a workshop with principal investigators and responsible researchers involved. During the workshop, practical recommendations were formulated, which were further discussed with and approved by the researchers involved in the PREFERABLE consortium. These recommendations are presented in the current report.

For each recommendation provided in this document, the relevant supporting findings from PERSPECTIVE are summarized. In addition, other considerations and perspectives as put forward by the participants of the workshop have been summarized. These considerations are based on the broader literature, previous own research, and clinical experience. Where applicable, these additional considerations are presented alongside the evidence from PERSPECTIVE.

[1] *ten Tusscher MR et al. Physical problems, functional limitations, and preferences for physical therapist-guided exercise programs among Dutch patients with metastatic breast cancer: a mixed methods study. Support Care Cancer. 2019 Aug;27(8):3061-3070. doi: 10.1007/s00520-018-4619-x.*

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The recommendations are aimed at different stakeholders. Recommendations could be aimed at **policy makers** (i.e., politicians, public health officials, or insurers), **health care managers** (i.e., hospital administrators, or clinical managers), **exercise professionals in health care** (i.e., physical therapists working in clinics and community settings, and clinical exercise physiologists), other **health care professionals** (anyone involved in the clinical care of people with MBC, including medical specialists, primary care physicians, nurses and nursing specialists, but not including the exercise professionals), and **non-governmental organizations**. For each recommendation, the relevant target group is indicated.

Generalizability

The PERSPECTIVE study included people with MBC and the recommendations refer primarily to this patient population. However, the expert panel believes that many of the findings are likely generalizable to the broader population of people with cancer. Therefore, several of the recommendations presented here may be more broadly applicable.

Future update of the recommendations

Recommendations may be updated or changed during the PREFERABLE project, as results from the EFFECT trial and new insights from another PREFERABLE work package: *Investigating barriers and facilitators for inclusion of exercise in health systems of the participating European countries (WP8)* become available.

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2 Recommendations

2.1 Executive Summary

The following main recommendations apply to all target groups of this document.

1. Patients with MBC should be **informed about possible benefits** of exercise and how (supervised) exercise programs could help resolve many of the barriers towards physical activity that they may experience.

2. Exercise counselling should be **embedded in the clinical pathways** and **health care professionals should take responsibility** for exercise counselling (assess, advise, refer) and for guiding a patient to reach the optimal amount of exercise to achieve benefits.

3. Exercise programs should be **individualized** to clinical state and circumstances, and where possible to accommodate individual preferences.

4. **Specific exercise programming** for people with (metastatic breast) cancer should be **implemented**, taking into account country-specific conditions and local infrastructure.

Recommendations per target group are provided in the tables on the following pages.

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2.2 Recommendations for policy makers

Recommendation 1

Policy makers should endorse and finance public health campaigns to inform MBC patients about expected health benefits from exercise.

PERSPECTIVE results supporting the recommendation	Patients **expect positive effects** on **physical outcomes** from physical exercise (focus groups and survey). Patients with MBC reported that maintaining or improving **endurance** and/or **muscle strength** were the main goals they would like to achieve by a supervised exercise program (survey). However, they had less knowledge about the effects of exercise on **psychological outcomes** or **fatigue** (survey).
Additional considerations	Public education about expected health benefits from exercise is currently mainly based on evidence obtained in the curative breast cancer setting. However, exercise effects in patients with MBC may be different from those in (breast) cancer patients without metastases and need to be updated continuously.

Recommendation 2

Policy makers should advocate for reimbursement by public and private health care insurers of the costs of exercise programs for MBC patients.

PERSPECTIVE results supporting the recommendation	Patients with MBC preferred supervision by an exercise professional to help them **overcome (physical) barriers** (focus groups). In addition, many patients reported that they did not know how much exercise they should do, and that they experienced a **fear of falls** or **injury** from exercise as a barrier for exercise (survey). Fifty-seven percent of MBC participants reported that they did not know whether their health care insurer currently reimburses exercise programs (survey). Only 9% of patients would be **willing to pay** more than 50 euros per month out of pocket in order to participate in a supervised exercise program, and for 38%, costs would be a barrier to exercising on a regular basis (survey).
Additional considerations	Although there is a need for supervised exercise, the amount that patients are willing or able to pay is in many cases lower than the costs of such a program. For each country, exercise reimbursement is different, as well as the costs for supervised exercise programs. In addition, within countries, reimbursement currently differs by health insurer. The health care professional can inform the patient about reimbursement or, minimally, recommend that they contact their health insurer to obtain information about this issue.

2.3 Recommendations for health care managers

Recommendation 3

Health care managers should ensure exercise counselling is structurally embedded in the clinical pathways and stimulate the development and financing of the necessary infrastructure for referral to and delivery of specialized exercise programming for MBC patients.

PERSPECTIVE results supporting the recommendation	Although patients with MBC have a **positive attitude** towards exercise, a large percentage of patients reported **barriers and insecurities** towards exercise (survey + focus groups). During the focus groups, patients mentioned that an exercise professional could help them to overcome these barriers. According to patients with MBC, the main barrier standing in the way for exercising on a regular basis is the lack of **access to specialized exercise programs** (survey). In addition, one of the main reasons to start or continue exercise on a regular basis would be to receive **personalized advice from a physiotherapist** (survey).
Additional considerations	Members of the medical team caring for patients with (metastatic breast) cancer should establish clear lines of responsibility regarding **exercise counselling**. To support participation in exercise programs, exercise should be **regularly discussed** and patients should be **referred** to appropriate programs. **Country-specific conditions** and **local infrastructure** should be considered when designing exercise programs to ensure accessibility for a large number of (metastatic breast) cancer patients. **Active counselling** will probably lower barriers towards exercise and referral is often required to gain access to i.e., physical therapy services.

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2.4 Recommendations for clinical exercise professionals

Recommendation 4

Clinical exercise professionals should incorporate previous and current physical activity levels of MBC patients in their consultations.

PERSPECTIVE results supporting the recommendation	Overall, having **previous positive physical** or **emotional experiences** from exercise were reported to be the main facilitators to start or continue exercising on a regular basis (survey). We found that patients with a **positive attitude** towards exercise and an active lifestyle before diagnosis often had a positive attitude after diagnosis (focus groups). Half of the patients (51%) believed that they knew **how much exercise** they needed to gain health benefits. However, only 6% of the survey participants were correct (140 to 160 minutes per week).

Recommendation 5

Clinical exercise professionals should tailor exercise programs to MBC patients' individual (health) conditions, abilities, and needs.

PERSPECTIVE results supporting the recommendation	Patients prefer flexibility with regard to the intensity of the exercise program because their physical condition varies over the course of their treatment (focus groups). In addition, patients may experience physical limitations (e.g., bone metastases), which require a tailored exercise program and close supervision or advice on correct execution of exercises (focus groups). Barriers to participating in exercise programs regularly mentioned by patients in the survey include pain, fear of falls or injury and being unsure how much exercise to do.
Additional considerations	Special attention should be paid to patients' **physical limitations** and **pain**. The exercise professional should provide a **safe environment**. Exercise professionals should actively ask and care about symptoms and modify exercise programs appropriately to match individual abilities. Clinical exercise professionals should be aware that the optimal exercise intensity and duration is not (immediately) achievable by all patients. Clinical exercise professionals should consider effective **patient education** about the safety and likely benefits of exercise as fundamental part of the treatment process. Clinical exercise professionals should **consult** the medical team in case of medical questions or for medical assurance. Clinical exercise professionals should provide the opportunity for **one-on-one** supervision to ensure appropriateness of exercises, correctness of execution and reassurance for patients with exercise-related fears. **Group training** options should be offered, ideally composed of people with (metastatic breast) cancer. If **home training** is preferred, an initial instruction and guided program is advisable.

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Recommendation 6

Clinical exercise professionals should help MBC patients to develop the necessary skills for self-directed resistance training.

PERSPECTIVE results supporting the recommendation	While increasing muscle strength was reported as one of the main goals the participants would like to achieve by exercising (focus group and survey), only 35% of the participants indicated having the necessary skills to engage in resistance-based exercises (survey).
Additional considerations	Skills for self-directed resistance training should include knowledge of which exercises are safe, proper form, how to progress or digress, and when to consult an exercise professional.

Recommendation 7

Clinical exercise professionals should help MBC patients choose exercise parameters to maximize the effects on parameters that pose barriers for them (i.e., fatigue, mood, or habit).

PERSPECTIVE results supporting the recommendation	Participants in the focus groups mentioned physical limitations and safety concerns as barriers to being physically active and they believed that an exercise professional could help them overcome these barriers by providing individually tailored programs and ensuring that exercises were carried out correctly. In addition, the support from an exercise professional would motivate them to be more physically active (focus groups). In the survey, patients reported feeling too weak (44%), tiredness (42%), a lack of motivation (35%), fear of falls or injury (33%) and shortness of breath (26%) as barriers (moderately to very much) standing in the way of exercising on a regular basis.
Additional considerations	(Supervised) exercise programs could help resolve many of the barriers mentioned above. Patients should receive support and be provided with techniques to overcome social-cognitive exercise barriers (e.g., planning) to increase exercise motivation and self-efficacy

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2.5 Recommendations for other health care professionals

Recommendation 8

Health care professionals should inform patients about health benefits of exercise, and encourage them to gradually increase their physical activity levels towards the optimal amount of exercise to achieve those benefits (150 min/week aerobic exercise and 2x/week strength training).

PERSPECTIVE results supporting the recommendation	Exercise recommendations **from their doctor** was the highest rated facilitator to exercise for patients with MBC in Poland (survey). We found that patients with a **positive attitude** towards exercise and an active lifestyle before diagnosis often had a positive attitude after diagnosis (focus groups). Half of the patients (51%) reported knowing **how much exercise** they should do to gain health benefits. However, only 6% of the survey participants were correct (140 to 160 minutes per week).
Additional considerations	Health care professionals should actively inquire about and attend to their patients' symptoms. A number of these symptoms can be reduced or relieved by exercise. Health care professionals should be aware of the patient's current exercise level and ability to be physically active and incorporate this in shared decisions about referral to an exercise specialist or program. Health care professionals should be aware that the optimal exercise intensity and duration is not (immediately) achievable by all patients.

Recommendation 9

Health care professionals should identify barriers to being physically active and educate MBC patients, which of those barriers would likely improve by exercising.

PERSPECTIVE results supporting the recommendation	Patients reported multiple **barriers** to exercising on a regular basis (survey). Some patients expect exercise to decrease their ability to perform daily activities (3%), increase their level of fatigue (4%) or worsen their pain (5%). MBC patients believed that a trained exercise professional could help them to **overcome barriers** and provide a **personalized exercise program** tailored to their needs and ability (focus groups).
Additional considerations	Some of the barriers (e.g., feeling too weak, tiredness, fear of falls or injury, shortness of breath), may be improved by exercising. Health care professionals should discuss with the patient whether supervision by an exercise professional could help them to overcome these barriers. Health care professionals should acquire knowledge via continuing education or self-study about the benefits of and barriers to exercise.

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Recommendation 10

Health care professionals involved in exercise counselling should discuss the return on investment of out-of-pocket expenses for exercise in relation to expected benefits.

PERSPECTIVE results supporting the recommendation	Of the MBC patients participating in the survey, 38% identified costs as a barrier to exercising on a regular basis. In addition, only 9% of patients would be **willing to pay** more than 50 euros per month to participate in a supervised exercise program (survey). Although participants' overall outcome expectancy was positive, 5% of the participants expected exercise to worsen their pain, and another 5% found it unlikely that exercise would be enjoyable (survey).
Additional considerations	In many cases, the willingness to pay would be insufficient for a supervised exercise program. From clinical experience, we know that patients are interested in what they can do themselves to improve their health. The health care professional can help put different self-care measures and their costs into perspective.

Recommendation 11

Health care professionals should acknowledge individual needs for social interaction and peer support and include this consideration in shared decision making when referring MBC patients to exercise programs.

PERSPECTIVE results supporting the recommendation	Many patients preferred group training, as they enjoy contacts with other people and the opportunity to socialize during exercise (focus groups). However, some patients favored exercising individually with an exercise professional (focus group). In all countries, the first preference for exercise supervision was supervision by either a fitness instructor or a physiotherapist (survey). The first most common preference for company to exercise with differed by country. Patients from Sweden preferred to exercise alone; in Poland, patients' first preference was to exercise with the general public; in Germany, patients preferred to exercise with other patients with cancer (survey). Patients from the Netherlands and Spain most often indicated no preference (survey).
Additional considerations	**Country-specific conditions** and **local infrastructures** need to be taken into consideration when determining how best to meet patients' individual needs and preferences with regard to exercising.

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Recommendation 12

Health care professionals and exercise professionals should encourage MBC patients to obtain information about the availability of reimbursement for exercise programs.

PERSPECTIVE results supporting the recommendation	57% of the survey participants did not know whether their current health insurance company reimburses exercise or rehabilitation programs for people with cancer. This percentage was similar across different countries: Germany 58%, The Netherlands 62%, Poland 41%, Spain 54% and Sweden 69%. For 38% of the participants, costs would be a barrier standing in the way for exercising on a regular basis (ranging from a little to very much).
Additional considerations	Ultimately, the individual patient is responsible for obtaining information from their health care insurer about reimbursement of exercise programs. Improving patients' knowledge about reimbursement may lower the cost-barrier for patients who qualify for such reimbursement, but who are currently unaware of this.

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2.6 Recommendations for non-governmental organisations

Recommendation 13

Non-governmental organizations should inform MBC patients about expected health benefits from exercise.

PERSPECTIVE results supporting the recommendation	Patients **expect positive effects** on **physical outcomes** from exercising (focus groups and survey). Patients with MBC reported that maintaining or improving **endurance** and/or **muscle strength** were the main goals they would like to achieve by a supervised exercise program (survey). However, they had less knowledge about the effects of exercise on **psychological outcomes** or **fatigue** (survey).
Additional considerations	Public education about expected health benefits from exercise is currently mainly based on evidence obtained in the curative breast cancer setting. However, exercise effects in patients with MBC may be different from those in (breast) cancer patients without metastasis and need to be updated continuously.

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PREFERABLE PERSPECTIVE study publications

Results of the PREFERABLE PERSPECTIVE study were published in:

Sweegers MG, Depenbusch J, Kampshoff CS, Aaronson NK, Hiensch A, Wengström Y, Backman M, Gunasekara N, Clauss D, Pelaez M, Lachowicz M, May AM, Steindorf K, Stuiver MM; PERSPECTIVE survey group. Perspectives of patients with metastatic breast cancer on physical exercise programs: results from a survey in five European countries. Support Care Cancer. 2023 Nov 13;31(12):694. doi: 10.1007/s00520-023-08124-4. PMID: 37955790; PMCID: PMC10643348.

Depenbusch J, Sweegers MG, Aaronson NK, Wengström Y, Backman M, Arraras JI, Schranz M, Büchler B, Lachowicz M, May AM, Steindorf K, Stuiver MM. PERSPECTIVEs on supervised exercise programs in people with metastatic breast cancer- a qualitative study in four European countries. Support Care Cancer. 2023 Apr 19;31(5):281. doi: 10.1007/s00520-023-07739-x. PMID: 37074497; PMCID: PMC10115708.

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