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CTRIAL-IE 23-05 Patient-led survey on information and communication needs of patients with Metastatic Breast Cancer in Ireland (Patient-led Metastatic Breast Cancer Survey)

Survey Questionnaire

Dear Participant,

What is the study about?

You are invited to take part in a research study in the form of an anonymous survey which aims to better understand the needs of patients with metastatic breast cancer (including secondary breast cancer, stage IV breast cancer and advanced breast cancer), with a particular focus on information and communication needs. The survey includes questions on patients experiences with metastatic breast cancer, as well as questions about your demographics, your diagnosis, your experience of living with metastatic breast cancer, prognosis, your personal diagnosis story and communication, sexual / intimacy / fertility impact, exercise, palliative care, financial burden and time toxicity.

The study has been developed by a patient with metastatic breast cancer in conjunction with a cohort of patients with the same disease and an interdisciplinary steering committee comprised of medical and radiation oncologists, allied health professionals, palliative care staff and doctors in training. The co Chief – Investigators of this study are Ms. Siobhan Gaynor (Patient Consultant Committee, Cancer Trials Ireland) and Prof. Seamus O'Reilly (Medical Oncologist, Cork University Hospital and Vice-Clinical lead Cancer Trials Ireland). This study is being conducted with Cancer Trials Ireland (http://www.cancertrials.ie) as part of their public patient involvement (PPI) initiative in cancer clinical research. This partnership will increase the reach of the study and facilitate analysis of the data received and dissemination of the findings. We plan for a total of 300 patients living with metastatic breast cancer to complete the survey so that we gather information on a broad range of experiences across the island of Ireland.

What will I have to do?

As part of this study, you will be required to answer questions in an anonymous online survey relating to your experiences of having metastatic breast cancer. Your full participation will take approximately 30 minutes (which includes reading this information sheet, reading and filling in the questionnaire).

What are the benefits?

The study's findings will help improve and understand further the impact that metastatic breast cancer has on the lives of patients in Ireland. It will investigate information and communication needs of patients. We hope that the results of this survey will be used to guide evidence-based changes in service provision and to also guide the implementation of new health and social care resources to optimise care for patients with metastatic breast cancer with particular emphasis on psychosocial and palliative care needs.

What are the risks?

As the survey contains questions of a personal nature reading and answering the questions may lead to increased anxiety. If you feel upset, distressed, or uncomfortable, you may withdraw from this study without any consequence. Simply discontinue and close the survey without answering any more questions. Support is available from cancer support groups and charities. Contact details and further information can be found at https://www.hse.ie/eng/services/list/5/cancer/patient/patlinks/

What if I do not want to take part?

Participation in this study is voluntary, and you can choose not to take part. It is entirely up to you.

What happens if I change my mind during the study?

If you begin the survey, you can stop answering the questions at any time with no consequence. You can simply close your browser and the responses you entered up until that point will be discarded. If you complete and submit the full survey, it will not be possible to withdraw your response at a later date because no personal identifying information will be collected and therefore, your response cannot be associated with you.

What happens to the information? Will my identity and my answers to the survey be kept private?

The collected information will be kept private and stored securely and safely on a SurveyMonkey® single password protected account managed by Cancer Trials Ireland. As you will not be asked to provide any identifying details, the data you provide will be anonymous. No personal data related to the device on which you complete the survey will be collected. At regular intervals during the survey, and following completion of the study the anonymous data will be downloaded from the SurveyMonkey® platform and saved as a database on a secure server at Cancer Trials Ireland. The anonymous data gathered in the study will be kept for ten years.

Who can take part?

You can take part if you are aged 18 years or older and have been diagnosed with metastatic breast cancer and are able to complete the online questionnaire independently or with the help of a friend

or relative.

What happens at the end of the study?

The information you provide will be pooled together with the information completed by other survey participants and the results may contribute to research publications and/or conference presentations. As detailed above, because no personal identifiable information will be collected, the information published will never be linked with any individual person.

What if I have more questions or need help understanding something?

If you have any questions or need help understanding something before deciding whether or not to take part, please feel free to contact the researchers Ms Siobhan Gaynor or Prof. Seamus O'Reilly via: mbcsurvey@cancertrials.ie

This study has obtained ethical approval from the RCSI Research Ethics Committee.

Thank you for taking the time to read this information. We would be grateful if you participated in this study.

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Consent and Eligibility

Do you consent to participate in this study?	**Yes**		**No**	

Please confirm that you are a patient in Ireland and Northern Ireland with metastatic breast cancer?	**Yes**		**No**	

Please indicate how you will complete the survey?	
• **Independently**	
• **With the help of a relative / friend**	
• **A combination of independently and with the help of a relative / friend**	

Demographics

1. Age								
2. Gender	**Male**		**Female**		**Non-Binary**			
3. Year of primary breast cancer diagnosis (if applicable) – please provide best estimate								
4. Year of metastatic breast cancer Diagnosis – please provide best estimate								

5. What is the highest level of education you have attained?	
• No formal education	
• Primary school	
• Junior / Intermediate Cert / GCSE (or equivalent)	
• Leaving Cert / A-Level (or equivalent)	
• Post-Leaving Diploma / Cert	
• Professional Qualification	
• University Primary Degree	
• University Higher Degree	

6. Metastatic breast cancer Subtype						
• Her 2 Positive	**Yes**		**No**		**Unknown**	
• Oestrogen Receptor Positive	**Yes**		**No**		**Unknown**	
• Progesterone Positive	**Yes**		**No**		**Unknown**	
• Triple Receptor Negative	**Yes**		**No**		**Unknown**	

7. County of Residence							
Antrim		Armagh		Carlow		Cavan	
Clare		Cork		Derry		Donegal	
Down		Dublin		Fermanagh		Galway	
Kerry		Kildare		Kilkenny		Laois	
Leitrim		Limerick		Longford		Louth	
Mayo		Meath		Monaghan		Offaly	
Roscommon		Sligo		Tipperary		Tyrone	
Waterford		Westmeath		Wexford		Wicklow	

8. County of Main Cancer Treatment Centre you are currently attending							
Antrim		Armagh		Carlow		Cavan	
Clare		Cork		Derry		Donegal	

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Down		Dublin		Fermanagh		Galway	
Kerry		Kildare		Kilkenny		Laois	
Leitrim		Limerick		Longford		Louth	
Mayo		Meath		Monaghan		Offaly	
Roscommon		Sligo		Tipperary		Tyrone	
Waterford		Westmeath		Wexford		Wicklow	

Persons understanding of their diagnosis and the narrative of how they received their own diagnosis. Knowledge of their own subtype and metastatic breast cancer journey. Access to medical information/medical notes.

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

9. Are you satisfied with your current level of knowledge about your metastatic breast cancer?	**Yes**		**No**	

If NO, for which aspects would you like to receive more information from your medical team? *(please tick all that apply)*	
• Personalised overview of your subtype and lesions location	
• First line, second line and third line treatment options	
• Clinical Trials	
• Other	
If other, please specify	

10. Do you currently have access to your medical information (scans and/or medical notes)?	**Yes**		**No**	

If NO would you like to have access?	
• All the time	
• Once a year	
• On request	
• Never	

11. In researching your metastatic breast cancer diagnosis which information sources are your 'go to'? *(Please put a number in the boxes, that are relevant to you, in order of priority)*	
• Irish Cancer Society	
• National Cancer Control Programme	
• Marie Keating Foundation	
• Breast Cancer Now UK	
• MacMillan UK	
• Cancer Research UK	
• Google Search	
• G.P.	
• Other cancer patients in a support group	

• Family and friends	
• Other sources	
• I do not research	

If you selected other sources, please specify	

12. Do you understand the term 'Oligometastatic disease'?	**Yes**		**No**		**Unknown**	
13. If yes, do you believe that Oligometastatic breast cancer is curable?	**Yes**		**No**		**Unknown**	
14. Do you understand the term '*de novo*' metastatic disease?	**Yes**		**No**		**Unknown**	
15. If yes, do you believe that *de novo* metastatic breast cancer has a better prognosis than primary breast cancer that has relapsed?	**Yes**		**No**		**Unknown**	

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Living with uncertainty

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

16. In your experience has your mental health been impacted since your metastatic breast cancer diagnosis?	**Yes**		**No**	

If yes, have you sought help / support from any of the following? *(please tick all that apply)*	
• Psychosocial Oncology service at your cancer centre	
• Social worker	
• Psychologist	
• Psychiatrist	
• Counselling service at Cancer Support Centre	
• Counselling service outside of Cancer Support Centre	
• G.P.	
• Family / friends	
• Yoga / Meditation / other holistic therapies	
• I have not sought any help or support	
• Other	
If other, please specify	

17. If you receive psychosocial support / counselling, how do you access these services?	**Face-to-face**	
	Online	
	Both	
	N/A	

18. Have you been prescribed medication for your mental health (low mood / anxiety) as a result of your diagnosis?	**Yes**	
	No	
	Prefer not to say	

19. In the week <u>before</u> your routine scans do you normally feel? *(Please tick all that apply)*	
• Anxious	
• Depressed	
• Fearful	
• Other	
If other, please specify	

20. How do you usually feel when you are waiting for the results of your scans? *(Please tick all that apply)*	
• Anxious	
• Depressed	
• Fearful	
• Other	
If other, please specify	

21. What other supports do you consider should be made available to those living with metastatic breast cancer? *(Please tick all that you believe would be helpful)*	
• Peer to Peer support, being matched with a person with a similar diagnosis	
• Support group for those living with metastatic breast cancer	
• Online support/counselling service	
• Provision by my treating cancer service of outline of mental health service supports available locally	
• Irish / UK website that is overseen by professionals working in the area of metastatic breast cancer	
• None – support available is adequate	
• Other	
If other, please specify	

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Prognosis - the issues and communication around a prognosis for individual patients, Optimal timing for information about prognosis.

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

22. Are you interested in finding out about your metastatic breast cancer prognosis / life expectancy? *(Please select the most applicable answer)*	
• Yes, I am interested in finding out and I have already been informed	
• Yes, I am interested in finding out and I have researched myself	
• Yes, I am interested in finding out but I have not received any information	
• No, I am not interested in finding out	

If No, please explain your reason(s):	
• To avoid mental anguish / distress	
• Feel information will be too complicated	
• Don't feel information would make a difference	
• My treating physician cannot estimate accurately	
• Other	
If other, please specify	

If Yes, and already informed or researched, what is the optimum time for receiving this information / researching in your view?	
• At the same time as the diagnosis of metastatic breast cancer	
• A few weeks up to 3 months after your diagnosis	
• Between 3 to 6 months after your diagnosis	
• More than 6 months after your diagnosis	
• After first line therapy has stopped working	
• Other	
If other, please specify	

23. At the visit during which prognosis is discussed, would you prefer if: *(please select all that apply)*	
• You were notified in advance that your prognosis would be discussed	
• You were asked if this information was something you wished to discuss	
• You were provided with the opportunity to bring someone along for this discussion	

• You were informed that a nurse/advocate would be present	
• Other	
If other, please specify	

Personal Diagnosis, Narrative, Are patients being open or closed with their children (persons under 18 years old) in their communication style about their diagnosis and prognosis?
(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

24. Who initially gave you your metastatic breast cancer diagnosis?	
• Consultant	
• Non-consultant/ Junior doctor – e.g. Registrar / SHO	
• Nurse	
• G.P.	
• Other	
If other, please specify	

25. Where were you given the diagnosis?	
• By Phone	
• G.P. Surgery	
• Hospital Clinic Room	
• Patient / Relative room	
• Inpatient hospital ward	
• Other	
If other, please specify	

26. How many people were present when you were given your diagnosis? *(Please count all who were present with you – medical personnel, family, friends, etc.)*	

27. What was their relationship to you? *(Please tick all that apply)*	
• Medical staff	
• Spouse / Partner	
• Sibling	

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• Child / children	
• Friend	
• Other	
If other, please specify	

28. How much time was allotted (approximately)?	
• Less than 10 minutes	
• 10 – 20 minutes	
• More than 20 minutes	

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29. Did you feel the time taken was:	
• Too much	
• Enough	
• Too little	

30. ***Do you have any additional information that you would like to add?*** *(please take care not to include any person's name or personal information for anonymity and privacy reasons)*	

31. Based on your personal story what improvements, if any, could be made to the diagnosis disclosure? *(Please tick all that apply)*	
• More time to ask questions	
• Nurse / Advocate present at discussion	
• An opportunity for questions after the diagnosis was disclosed	
• Discussions to take place in relative's room / private space	
• None – no improvements suggested	
• Other	
If other, please specify	

32. What aspects would you like more information or support on? *(Please tick all that apply)*	
• Speaking with children about the diagnosis	
• Speaking with children about prognosis	
• Speaking to the wider family and friends about your diagnosis	
• Prognosis for my metastatic breast cancer sub-type	
• Updates as new information is published	
• Opportunity to have longer discussions (more than 10 mins) with medical team	
• None – no additional support or information needed	
• Other	

If other, please specify	

33. Do you have children (aged under 18) in your life?	**Yes**	
	No	
	Prefer not to say	
If YES, what age(s) are the child(ren) *(please select all that apply)*		
• 0-2 years old		
• 3-5 years old		
• 6-8 years old		
• 9-11 years old		
• 12-14 years old		
• 15-18 years old		

34. Have you been open about your <u>diagnosis</u> with:						
• Your partner	**Yes**		**No**		**N/A**	
• Your children	**Yes**		**No**		**N/A**	
• Your wider family (parents / siblings, etc.)	**Yes**		**No**		**N/A**	
• Your close friends	**Yes**		**No**		**N/A**	
• Your community	**Yes**		**No**		**N/A**	
• Your workplace	**Yes**		**No**		**N/A**	

35. Have you been open about your <u>prognosis</u> with:						
• Your children	**Yes**		**No**		**N/A**	
• Your wider family (parents / siblings, etc.)	**Yes**		**No**		**N/A**	
• Your close friends	**Yes**		**No**		**N/A**	
• Your community	**Yes**		**No**		**N/A**	
• Your workplace	**Yes**		**No**		**N/A**	

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Sexuality/intimacy/fertility aspects

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

36. Have you been offered advice or support on the effects of metastatic breast cancer and the side effects of treatment can have on your sexual wellness?	**Yes**	
	No	
	N/A	
	Prefer not to say	

37. Have you experienced any changes in your sex life?	**Yes**	
	No	
	N/A	
	Prefer not to say	

If yes, have you sought medical advice?	**Yes**	
	No	
	Prefer not to say	

If you have not sought medical advice, why not? *(please tick all that apply)*	
• Uncomfortable / embarrassing topic	
• Fear of being dismissed / misunderstood	
• Prefer not to say	
• Other	
If other, please specify	

38. Do you consider that sufficient information on the impact of your treatment on fertility was provided by your medical team?	**Yes**	
	No	
	N/A	
	Prefer not to say	

39. As a result of the treatment you received for your cancer have you experienced an early menopause or changes in your menstrual cycle?	
• No change – I was menopausal prior to treatment	
• No change – my periods continued during treatment	
• My periods stopped temporarily *(Stopped and then returned when treatment stopped)*	
• My periods stopped permanently during and after my treatment for cancer	
• My periods have stopped and I'm currently on treatment for cancer	

40. If you have experienced menopausal symptoms during your treatment have you asked for support? *(Symptoms include hot flushes, night sweats, urogenital symptoms as well as mood and sleep disturbance)*	**Yes**	
	No	
	N/A	
	Prefer not to say	

If yes, what support did you receive? *(Please tick all that apply)*	
• Information on menopausal symptoms and symptom management	
• Referral to website	
• Referral to complex menopause clinic	
• No supports were offered	
• Other	
If other, please specify	

Were you satisfied with the supports offered?	**Yes**		**No**	

If no, what support do you feel should have been provided? *(Please tick all that apply)*	
• Information on menopausal symptoms as standard of care for all women undergoing cancer treatment	
• Referral to website	
• Referral to complex menopause clinic	
• Other	
If other, please specify	

Exercise and Physical Activities

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

41. Since your diagnosis have you started, or increased your exercise activities?	**Yes**		**No**	

42. Since your diagnosis have you reduced your exercise activities?	**Yes**		**No**	

43. How many minutes per week (on average) do you spend engaging in physical activities (including exercise, housework, walking and gardening)?	
• Less than 60 minutes per week	
• Between 60 and 90 minutes per week	
• Between 90 and 120 minutes per week	
• Between 120 and 150 minutes per week	
• More than 150 minutes per week	

44. Do you consider that your cancer places limitations on your ability to exercise?	**Yes**		**No**	

If yes, have you been advised that this is the case by your medical team?	**Yes**		**No**	

45. Do you have bone metastases?	**Yes**		**No**	

If yes, have you been advised by your medical team that it is safe to exercise?	**Yes**		**No**	

If yes, have you been advised of specific limitations for exercising by your medical team?	**Yes**		**No**	

46. Have you availed of any of the following medical exercise programmes? *(Please tick all that apply)*	
• Exwell	
• Move More	
• Private trainer	
• Local gym	
• Other	
If other, please specify	

Palliative Care and Supportive care

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

47. Have you been advised by your medical team of the palliative care supports / supportive care in your area?	**Yes**		**No**	

48. Which of the following services do you consider to be provided by palliative care? *(Please tick all that apply)*	
• Pain Management	
• Symptom Management	
• Fatigue Management	
• Psychosocial / Mental Health Supports	
• Family supports	
• Quality of life care	
• End of Life care	
• Other	
If other, please specify	

49. How amenable would you be to a palliative care referral by your medical team? *(Please tick all that apply)*	
• I would certainly consider it	
• I would be unsure about the referral	
• I would accept the referral	
• I would refuse the referral	
• I would take my families opinions into consideration	
• I would need more information in order to decide	

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Financial Burden – Extent to which a diagnosis of metastatic breast cancer may impact personal financial situation

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

50. My out-of-pocket medical expenses are more than I thought they would be *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

51. I worry about the financial problems I will have in the future as a result of my illness or treatment: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

52. I know I have enough money in savings, retirement or assets to cover the cost of my treatment: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

53. I feel I have no choice about the money I spend on medical care: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

54. I am frustrated that I cannot work or contribute as much as I usually do: *(Please tick all that apply)*

• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

55. I am satisfied with my current financial situation: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

56. I am financially stressed: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

57. I am able to meet my monthly expenses: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

58. I feel in control of my financial situation: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

59. My illness has been a financial burden on me and my family: *(Please select the most appropriate answer)*	
• Strongly agree	
• Somewhat agree	
• Neither agree nor disagree	
• Somewhat disagree	
• Strongly disagree	

Time Toxicity – Time consumed by appointments, treatments, side effects and managing and procuring medications

(For any question where you can type a response, please take care not to include any person's name or personal information for anonymity and privacy reasons)

60. On average, how many days per month (28 days) do you spend visiting the hospital?	
• None	
• 1 – 3 days	
• 4 – 7 days	
• More than 7 days	

61. What are the reasons for these visits? *(Please tick all that apply)*	
• Systemic therapy including infusions / subcutaneous injections	
• Radiotherapy	
• Scans and x-rays	
• Symptom control	
• Blood tests	
• Management of side-effects from treatment	
• Management of complications from cancer	
• Other	
If other, please specify	

62. How long do your hospital visits take on average?	
• Less than 60 minutes	
• 1 hour – 3 hours	
• 4 – 6 hours	
• More than 6 hours	

63. In the past six (6) months, how many times has your visit to the hospital involved blood tests?	
• None	
• 1 time	
• 2 – 3 times	
• 4 – 5 times	
• More than 5 times	

64. In the past six (6) months, how many visits to the hospital have you had which involved scans or X-rays (this includes CT scans, X-rays, MRI or bone scan)?	
• None	
• 1 time	
• 2 – 3 times	
• 4 – 5 times	
• More than 5 times	

65. In the past six (6) months, how many visits have involved infusions / subcutaneous injections?	
• None	
• 1 time	
• 2 – 3 times	
• 4 – 5 times	
• More than 5 times	

66. In the past six (6) months, how many visits involved clinic or doctor's office visits?	
• None	
• 1 time	
• 2 – 3 times	
• 4 – 5 times	
• More than 5 times	

67. In the past six (6) months, how many visits have you had to the oncology day ward / acute oncology service unit?	
• None	
• 1	
• 2-3	
• 4-5	
• More than 5 visits	

68. In the past six (6) months, how much time was spent in the oncology day ward / acute oncology service unit?	
• Less than 10 hours	
• 10 – 20 hours	
• 20 – 30 hours	
• More than 30 hours	

69. In the past six (6) months, how many visits have you had to the hospital emergency department for medical care?	
• None	
• 1	
• 2-3	
• 4-5	
• More than 5 visits	

70. If you visited the hospital emergency department for medical care over the past six months, how long did you spend in the emergency department?	
• Less than 6 hours	
• 6 – 12 hours	
• 12 – 24 hours	
• More than 24 hours	

71. In the past six (6) months, how many physiotherapy visits have you had for lymphoedema care?	
• None	
• 1	
• 2-3	
• 4-5	
• More than 5 visits	

72. In the past six (6) months, how many psychooncology visits have you had?	
• None	
• 1	
• 2-3	
• 4-5	
• More than 5 visits	

73. Have you had any admissions to hospital for medical care over the past six months?	
• None	
• 1 time	
• 2-3 times	
• 4-5 times	
• More than 5 times	

If you have been admitted to hospital for medical care, how many days have you spent admitted to hospital over the past six months?	
• None	
• Less than 5 days	
• 5 – 10 days	
• More than 10 days	
74. How long do you spend travelling for medical visits to the hospital or other care facilities? *(Please consider the travel time to the location where you have the majority of appointments)*	
• Less than 30 minutes	
• 30 – 60 minutes	
• 60 – 90 minutes	
• 90 – 120 minutes	
• More than 120 minutes	

75. How do you get to the hospital? *(please indicate the main mode of transport)*	
• Drive myself	
• Driven by family / friends	
• Taxi	
• Bus / Train	
• Walk / Cycle	
• Hospital transport	
• Volunteer service / transport	
• Other	
If other, please specify	

76. How much time in the past six months have you spent in total managing your metastatic breast cancer? *Please select your best estimate considering all appointments related to treatment, medical review, side effect management, physiotherapy, audiology, counselling, psycho-oncology, travel time and time spent managing medications, etc.*	
• Less than 30 hours	
• 30 – 45 hours	
• 45 – 60 hours	
• More than 60 hours	

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