



METASTATIC BREAST CANCER ALLIANCE **THOUGHT LEADER SURVEY REPORT**

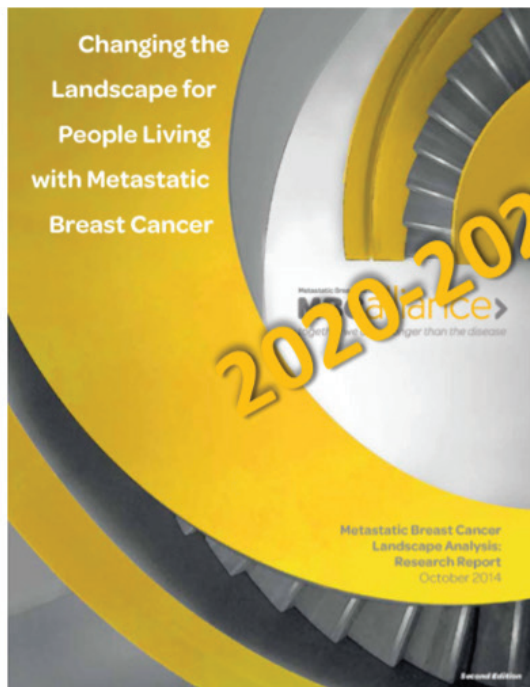
EXECUTIVE SUMMARY



Metastatic Breast Cancer Alliance, New York, NY; Breast Cancer Research Foundation, New York, NY

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In 2014, the Metastatic Breast Cancer Alliance (MBCA) published a *Landscape Analysis entitled Changing the Landscape for People Living with Metastatic Breast Cancer*. Chapter 2 of this report included input from Key Opinion Leaders (now called Thought Leaders or TLs) about the landscape of research in MBC. In 2020, the MBCA initiated a project to update this section of Chapter 2 of the Landscape Analysis. The MBCA also sought to report the current landscape of MBC research and to gather knowledge to inform the 5-year MBCA strategic plan beginning in 2021. As a first step towards these goals, in Fall 2020, the MBCA conducted qualitative research, which included 20 interviews with TLs with knowledge of MBC research. A breadth of knowledge was sought, and thus interviewees comprised from those working in academia, industry, government, nonprofit organizations, and the research community. Interviews in 2020 also included people living with MBC and MBC patient advocates to provide the voice and perspective of people living with MBC. Interviews were conducted on Zoom by four representatives of MBCA member organizations who have a research background. Topics covered in the interviews included recent advances in MBC research, near-term impacts, new treatments, clinical trials, new technologies, roles for advocates in MBC research, and roles for the MBCA.



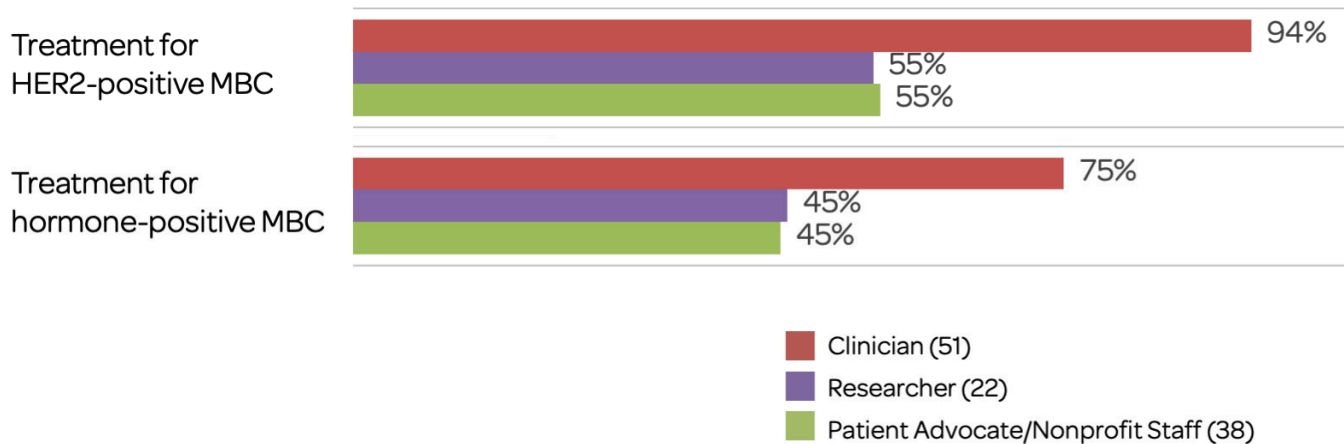
CHAPTER 2: LANDSCAPE ANALYSIS OF MBC RESEARCH

Based on the knowledge gathered from these interviews, survey questions were developed. The objectives of the survey were to

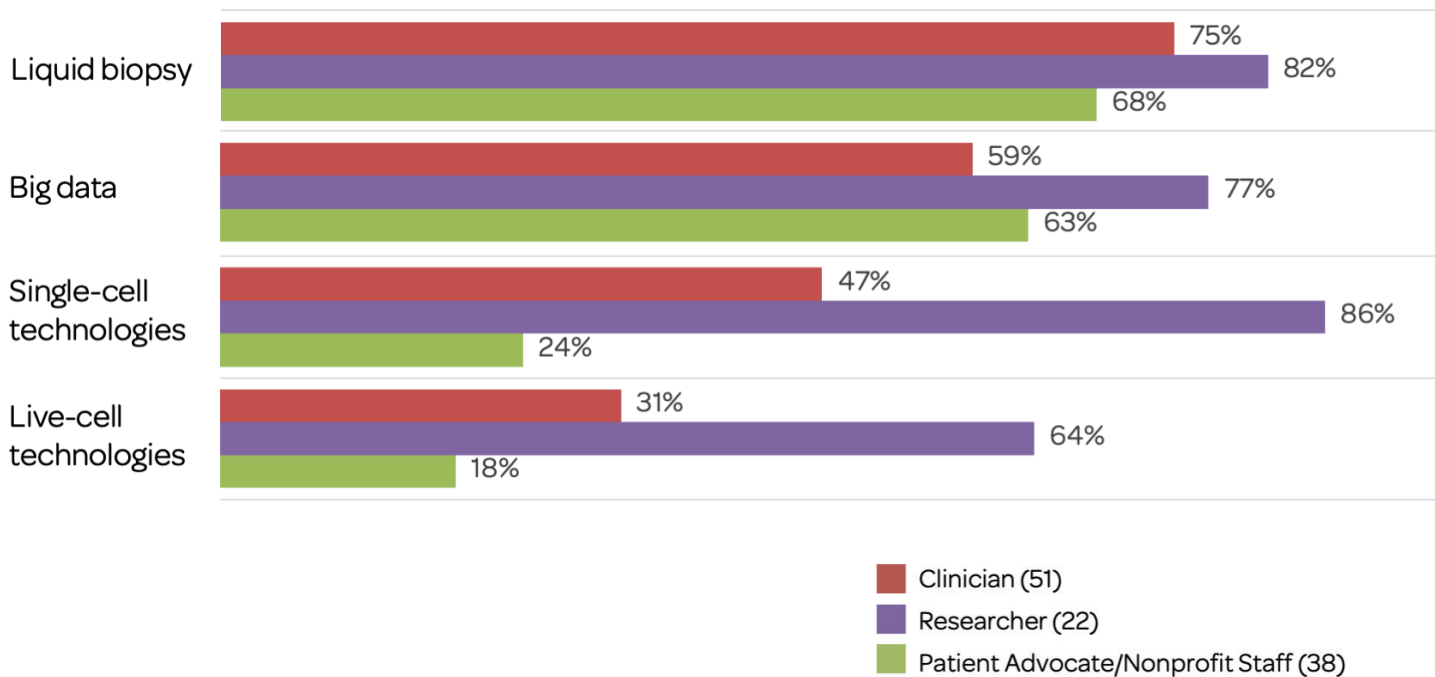
- 1. Understand the impact of recent **progress** (~5 years) in MBC research on improving outcomes and quality of life (QOL) for individuals living with MBC
- 2. Assess the **potential** of new treatments to impact the lives of those living with MBC in the next ~5 years
- 3. Assess areas of **research** and **technologies** with the most **potential** to advance our understanding of MBC
- 4. Understand the importance of various aspects of **clinical trial participation to impact people living with MBC**
- 5. Inform **priorities** and roles for the MBCA in the next ~5 years

The digital survey that was developed was distributed to 167 TLs (with overlap from the 20 TLs who participated in the interviews). The survey was open in March and April 2021. A total of 119 confidential surveys were completed (71% completion rate). The respondents self-identified their role; 43% were clinicians (mostly medical oncologists), 32% were nonprofit staff members or patient advocates, and 18% were researchers (mostly lab scientists). Pharmaceutical TLs also participated in the survey. Participants rated 90 items in four topics (Research Progress/5-Year Look Back, Research Potential/Next 5 Years, Clinical Trials, MBCA Priorities). Survey participants were asked to rate each item according to its impact on patient outcomes and QOL on a scale from 1 to 5. The full report summarizes responses of 4 or 5 (combined), which indicate major or significant progress or potential; very important or extreme importance (in the clinical trials section); or high or very high priority (in the MBCA priorities section).

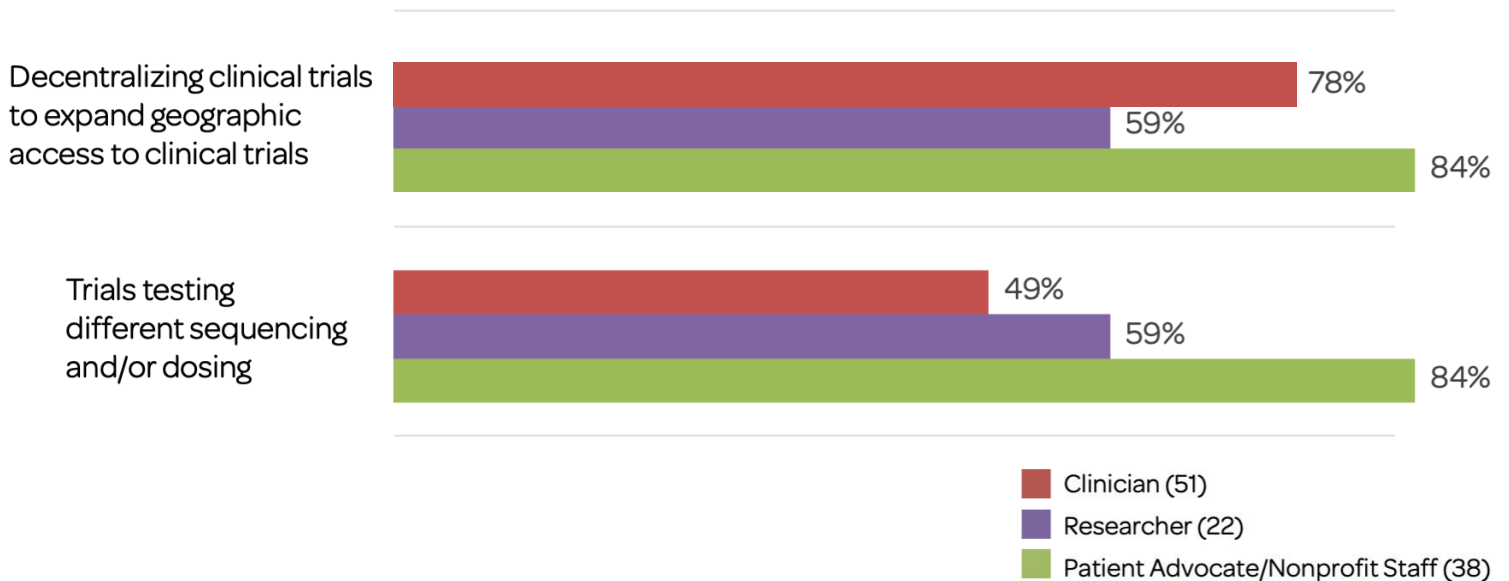
Major or significant **progress** in the last ~5 years was reported for some treatments (for HER2+ and ER+ MBC) and in understanding the role of the immune system and tumor microenvironment. Greater differences between stakeholder groups than expected were noted. Perceptions of progress differed by role (see below and Figures 4-6 in the main report). For example, patient advocates/nonprofit staff and researchers reported lower progress (55% selected a score of 4 or 5) for treatment for HER2+ MBC than clinicians, who were very enthusiastic about progress in this area (94% selected 4 or 5; below and Figure 4). In addition, researchers rated the amount of progress in basic research made over the past 5 years higher than clinicians and patients, perhaps because a lot of time passes between research progress and its impact on patient outcomes.



The roles of the immune system and tumor microenvironment were identified as having major or significant **potential** to improve patients’ outcomes and/or QOL in the next ~5 years, as was liquid biopsies. Researchers were more enthusiastic about many aspects of basic research, biomarkers, and technologies, perhaps due to familiarity with these topics (see below and Figures 7-9). Large gaps may be present among the groups in knowledge about specific technologies including live-cell technologies and single-cell technologies; however, big data enthusiasm was high in all groups (below and Figure 9).



Areas of particular importance in **clinical trials** included increasing trust and diversity, educating patients about clinical trials, increasing funding for biospecimen collection and storage, increasing the number of clinicians who offer trials to their patients, decentralizing trials, and reducing eligibility requirements. Notable differences in aspects of clinical trials to impact patient outcomes were seen. For example, patient advocates/nonprofit staff believe that testing different sequencing and/or dosing is much more important than clinicians (84% of patient advocates/nonprofit staff vs 49% of clinicians selected 4 or 5; see below and Figure 13). Patient advocates/nonprofit staff and clinicians rated decentralization of clinical trials more important than did researchers (below and Figure 11; 84% of patient advocates/nonprofit staff and 78% of clinicians vs 59% of researchers selected 4 or 5). Researchers were more likely than clinicians or patient advocates/nonprofit staff to answer “don’t know” or “not applicable” to questions about clinical trials, suggesting a lack of knowledge about clinical trials.



The following areas were identified as **priorities for the MBCA**: advocating for continued investment in basic research and clinical trials, advocating for funding for patient-reported outcomes in clinical trials, increasing patient and investigator collaborations in clinical trials, improving patient awareness about clinical trials, and promoting conversations about MBC in all breast cancer communities. A surprising observation was that only 59% of researchers indicated that facilitating discussion with pharma for patient-centric clinical trial design has high or very high importance, whereas 79% of patient advocates/nonprofit staff and 80% of clinicians rated this as a 4 or 5 (see below and Figure 16). The low percentage among researchers may reflect a lack of understanding that it is through such discussions that restrictive clinical trial requirements can be removed. Another surprising difference was that patient education about the value of

patient registries was a relatively lower priority to clinicians and patients (53% of clinicians and 61% of patient advocates/nonprofit staff vs 82% of researchers selected 4 or 5; below and Figure 15), raising the question of how familiar oncologists, surgeons, and radiologists who answered the question are with registries.



Advocates have different backgrounds and skill sets, which may partially explain some of the differences in reporting of areas of importance. Patient advocates selected the researchers who were invited to answer this survey. These scientists likely responded based on their individual experience, whereas advocate responses likely reflect their perception of scientists as a group. Thus, the survey results reflect different perspectives.

The survey results reflect different perspectives and point to many directions for ways to make progress in improving the lives of people living with MBC.

The observations from the survey do not all point in the same direction for a pathway to make progress for people living with MBC. Many avenues can be explored to improve outcomes and QOL for people living with MBC. Possible actions for the MBCA include:

- > Education for patients and advocates in various areas of basic research, clinical trial endpoints, and genetic testing.*
- > Education for researchers about the realities of living with MBC and meaningful collaborations with patient advocates.*
- > Education for clinicians about the value of patient registries to researchers.*
- > The MBCA can perform an audit/inventory of efforts and gaps by its member organizations that pertain to clinical trials, education, collateral damage, and conversations about MBC in all breast cancer communities.*
- > The MBCA can advocate and continue to advocate for liquid biopsies in clinical trials, continued availability of telehealth, increased access to serial biopsies from all populations, data sharing, patient-centric trial design, and including patient-reported outcomes in clinical trials.*
- > The MBCA can support and continue to support collaboration among stakeholders, big data efforts, interactions between the MBCA and its member organizations to reach common goals, and the value of MBC Connect.*

Priorities for the MBCA include education for the different stakeholder groups, an audit of efforts by member organizations, and various advocacy efforts.