

A patient survey of artificial intelligence in metastasis research

Deciphering Metastasis with Multimodal Artificial Intelligence Multimodal Foundation Models - DECIPHER-M

1st Patient Survey "Use of AI tools to better predict, detect and treat cancer metastasis"

Introduction

The DECIPHER-M project aims to assess the potential of the latest generation of artificial intelligence based tools, the so-called generative AI or foundation models built using large amounts of clinical data (patient reports, radiology images, pathology reports, molecular profiling), to ultimately improve clinical management and outcome of metastasis. To tailor our research program to patients' needs already during the conceptualization, together with our partner patient organizations, we connected with patients and caregivers to assess their medical needs, including questions, concerns and expectations from an AI-based tool to effectively implement their perspective. Particularly, the design and dissemination of the survey have been supported by *Deutsche Sarkomstiftung* (sarcoma), *Sarcoma Patients Advocacy Global Network* (SPAGN; sarcoma), *Allianz gegen Brustkrebs* (breast cancer), *Semi-Colon* (GI cancers), *Prostatakrebs-Selbsthilfegruppe* (prostate cancer), *Deutsche Leberhilfe* (liver cancer) as well as members of the *NCT Patientenforschungsrat* (different cancer entities).

Results

Patient characteristics

Our first survey on the topic of AI tools for better prediction, detection, and treatment of metastasized cancer was able to garner remarkable attention and participation, thanks to the proactive engagement of numerous patients and patient organizations. Within a mere span of approximately two weeks, we received 650 responses from cancer patients and/or their caregivers. About 11% patients belonged to the age group <40. 44% patients belonged to the age group s0-60, giving an excellent cross section of patient populations voicing their opinions and concerns (Figure 1).



Figure 1: Overall age distribution of respondents grouped in three age categories <40 years, 40-60 years and >60 years.

Entity distribution

The survey was distributed among patients and caregivers by patient organizations mentioned above and disseminated on social media. Among 650 participants, almost 40% had sarcoma as their primary diagnosis, which on the one hand highlights the unmet medical need of patients suffering from this large, heterogeneous and rare group of cancers, and demonstrates their high desire to contribute to scientific advancement benefiting their community. On the other hand, it portrays the successful outreach efforts of the patient organization network, bound by the need for support for these difficult to diagnose and treat cancers. Patients with additional cancer types investigated in our proposal, specifically breast cancer, also participated in the survey, thereby underlining the relevance of this effort for our proposal and importantly, broad reach of our patients and patient organizations (Figure 5).



Figure 2: Cancer type distribution among respondents

Metastasis burden

About 40% of patients participating in the survey responded that they had been diagnosed with metastatic disease, with an average number of 8.7 metastatic nodules. About 70% of these patients had under 1-5 metastases detected at diagnosis of metastatic disease; around 28% had between 6-80 metastases, and four patients reported several metastatic nodules between 100-240, suggesting heavy metastasis burden affecting participating patients.



Figure 3: Number of metastases reported grouped in patients with 1-5 metastases, 6-80 metastases and 100-240 metastases.

Moreover, the survey highlights the crucial importance of early detection, revealing that 68% of respondents were initially diagnosed at the M0 stage, indicating that cancer had not yet spread beyond its site of origin at the time of diagnosis (see Figure 4). Nonetheless, 17% were diagnosed at the M1 stage, signifying metastasis to other parts of the body, and 11% at the Mx stage, where the existence of metastases could not be precisely determined at the time of diagnosis. About 3% of respondents were uncertain about the stage of metastasis at their initial diagnosis.



Figure 4: Metastasis stage at first diagnosis.



Figure 5: Largest metastasis at time of diagnosis

Of those diagnosed with metastasis almost 37% were diagnosed with metastasis smaller than 1 cm, 37% with metastasis of 1-3cm and 26% with metastasis even bigger than 3 cm (see Figure 5). These numbers highlight the need for early detection, improved sensitivity of detection, and metastasis risk prediction strategy at the primary diagnosis stage. Particularly, in the light of about 70% of patients having no metastasis at the primary diagnosis, a substantial proportion of them receiving first diagnosis of metastasis at the size of >3cm underlines the need for improved risk prediction and detection, a gap that could potentially be addressed by the Albased foundation model envisioned in the proposal.



Figure 6: Size of metastasis detected in patients first diagnosed at M0



Experience around disease monitoring and quality of life

Figure 7: Number of scans grouped in 0-20 scans, 21-40 scans, 41-60 scans and 81-100 scans.

Responding patients reported a significant number of CT and or MRI scans, ranging from 1 to 100, likely correlating with disease burden or risk of progression (Figure 7). As each scheduled scan is an important milestone in diagnosis, therapy or surveillance, with an uncertain outcome heavily affecting a patient's prognosis, we asked the patients to share their feelings and experience prior to scans.



Figure 8: Feelings before a scan or check-up.

Unfortunately, but not unexpectedly, we received feedback weighing towards fear and restlessness, and only a fraction of people (28%) described their feelings as either positive or neutral (Figure 8). The free-text answers highlighted further important aspects:

• Increased restlessness and panic in the time between scan, diagnosis and recommendation

- Long waiting times for results
- Local examination of the organ site raising concern for potential undetected lesions
- Concern to receive non-tailored treatment
- Absence of specialized care and personalized treatment

Many, but not all these concerns could be addressed by supporting clinicians with better diagnostic tools, and tools to integrate comprehensive information of a patient ranging from histopathology slides to CT scans to multi-omics profiling data, to enable quicker, more accurate diagnosis, and prescribe personalized treatment approaches even at non-specialized centers. Such multi-level correlations are only possible and made available by AI-based foundation models that integrate multimodal data and can be readily utilized by medical providers outside the specialized cancer centers to steer surveillance and treatment.

Related Quotes

"Große Angst und Unruhe vor den Terminen bis nach den Befundbesprechungen. Danach dann Wechsel zwischen Hoffnungslosigkeit und Hoffnung, Angst, Trauer, Unwohlsein, Unruhe"

"Ewiges Warten auf die Ergebnisse"

"Die Diagnostik beschränkt sich auf die Brust. Es verunsichert mich, dass das ausreichen soll."

"Kampf um Diagnose"

"Leider dauert es zw. Untersuchung und Befund zu lange und erhöht unnötigerweise den psychologischen Druck"

"Radiologie sehr unpersönlich, oft kein Arztkontakt, Untersuchung erfolgt oft nicht in Hinblick auf die individuelle Erkrankung und Person, wozu fülle ich einen Anamnesebogen aus? Angst bis zur Ergebnis Besprechung"

"Da ich nicht sofort in ein Sarkomzentrum vermittelt wurde, ist mir viel wertvolle Zeit verloren gegangen."

Quality of life



Figure 9: Biggest factor influencing patients' quality of life.

One of the most important aspects beyond direct treatment success is the quality of life (QoL) of the patients undergoing treatment or those in remission. About 24% of the participants regardless of their current disease stage lived in the fear of metastasis, an additional 27% were concerned about detection of new tumors diagnosed in themselves or a family member (Figure 9). Treatment-associated side effects were reported to most severely affect QoL for 26% of patients. Finally, open text answers highlighted additional factors, such as burden of intensity of radiotherapy or the fear of progression and death as main inhibitors to their QoL. However, surprisingly some patients' QoL has been positively influenced by the diagnosis and they have "...gained a different perspective." These findings underline the urgent need for research in the direction of effective and well-tolerated treatment options.

Related Quotes

"Man traut sich nicht größere Pläne für die Zukunft zu fassen, da das Lebensende seit der Diagnose viel näher ist"

"Sozioökonomische und strukturelle Behindertenfeindlichkeit in Intersektion mit anderen Marginalisierungen"

"Die viele Zeit, die beim Warten bei den ständigen Arztterminen verloren geht, könnte durchaus schöner verbracht werden"

"Meine Lebensqualität hat sich durch die Krebserkrankung über die Jahre eher positiv verändert, ich habe andere Blickwinkel bekommen."

"Nach 14 Jahren wird man ruhiger"

"Ich habe Respekt vor der Ernsthaftigkeit der Erkrankung, aber ich werde mir Gedanken über alles Weitere machen, wenn es eintreffen sollte. Zuvor lebe ich normal und genieße alles Gute noch bewusster. Ich bin nun leicht gehbehindert, aber das ist gut zu meistern. Es gibt Schlimmeres!"

Opinions around AI-based approaches for clinical management of metastasis

This survey has provided invaluable insights into patients' opinions on application of AI in detection, prediction and management of metastasis, particularly highlighting the overwhelming support among participants of all age groups (95% in favor, 4% against and 1% unclear, Figure 10). Among respondents under 40, a staggering 97% expressed favorability towards using AI tools for improved metastasis detection, with only 3% expressing opposition. Intriguingly, within the 40-60 age group, also 97% voiced support for AI utilization, while 2% opposed and 1% remained uncertain. Among respondents over 60, 92% were in favor, 7% against, and 2% uncertain. This indicates widespread enthusiasm across age groups for the integration of AI in cancer treatment with a slight bias towards increased uncertainty in older patients (Figure 11).



Figure 10: Responses to question whether AI tools should be used for better detection of metastasis.



Figure 11: Age distribution of respondents to the question whether AI should be used.

Among those who opposed the use of AI, a detailed breakdown of reasons reveals crucial insights: 48% feel they are not adequately informed to decide, 32% express a lack of trust in AI tools in general, 12% assert that AI can only be a part of a holistic approach, and only 8% question its overall usefulness (Figure 12). These findings underline the pressing need for improved information strategies towards patients regarding the emerging topic of AI tools in medicine. It is evident that a significant portion of respondents currently opposed to the use of AI tools in cancer treatment, harbor reservations due to insufficient understanding or trust issues.



Figure 12: Opinions against the use of AI are grouped in four categories: "Question usefulness", "No trust", "AI only as part of a holistic approach", "Need more information".

This preliminary data highlights the requirement for targeted information initiatives aimed at empowering patients with the knowledge needed to make informed decisions, which we will address within our patient involvement activities by information events, updates on our on-going research and latest advances and benefits of AI in cancer in general. This will be conducted in lay language to ensure reachability, of which the patients and patient organizations will again guarantee a broad dissemination of the information.

Related Quotes

"Alleinige KI ist nicht ausreichend, ein erfahrener Arzt, ordentliche Diagnostik und viel mehr Aufklärung ist wichtig. "Und falls der behandelnde Arzt keine Erfahrung in diesem Gebiet hat, muss er ehrlich sein und die Pat zu einem Spezialisten überweisen (hab da schlechte Erfahrungen gemacht)."

"Der Mensch soll in solch schwerer Zeit vom Menschen betreut werden"

"Hohes Misstrauen bezüglich Differenzierung und individualisierung, vorgehen nach Fragebogen und "Punktesystem"

"Wie erfolgt die praktische Realisierung?"

Willingness for data sharing for AI

Finally, we sought to assess the willingness of patients to support continuous development of AI-based approaches for improved clinical care by sharing their own clinical data, ranging from patient reports, pathology and radiology findings, treatment course and similar. About 65% of patients answered this question with a yes, about 9% a clear no with reasoning, and about 26% were willing to share specific types of data.



Figure 13: Willingness to share own records.

Inspection of free text responses revealed several factors underlying the concern with data sharing:1) concern about effective pseudonymization 2) hesitation with sharing specific data types and importantly 3) complete or in-part unavailability of the data with the patients themselves. These responses amplify the urgent need for digitalization of patient records that are easily accessible for the patients. The general willingness and even enthusiasm in patients of all age groups to share the data for AI or research purposes in general should be a strong argument against the current laws in Germany hindering true patient-partnered research initiatives such as Count-me-in (https://joincountmein.org/). Data protection and patient protection should no longer be contrasted but combined in a joint solution in the interest of medical innovation.

Related Quotes

"Alle die dafür notwendig sind, das Leben von Patienten mit Metastasen in Zukunft zu verbessern."

"... Ich glaube, dass eine KI den Verlauf besser im Blick gehabt hätte."

"Solange es anonymisiert ist, ist man bereit zur Verfügung zu stellen"

"Ich denke, dass das PET-CT am meisten Sinn macht. Ich kann es allerdings nicht anonymisieren."

"Bildgebungen liegen mir nicht vor, allerdings Histologien und Arztbriefe."

"Unterlagen sind nicht in meinem Besitz"

Collectively, the successful dissemination and enthusiastic participation of all POs and patients uncovered multiple important aspects around clinical management of metastasis, which at least in part could be addressed by the work envisioned in our proposal. We hope to continue this fruitful collaboration in the framework of the proposal, and already thank all the POs and patients for taking the time for the survey, generously sharing their experiences on this difficult condition and, above all, for being a part of the DECIPHER-M team.