Count Me In's OS & LMS Patient-Partnered Research Projects

Osteosarcoma Project

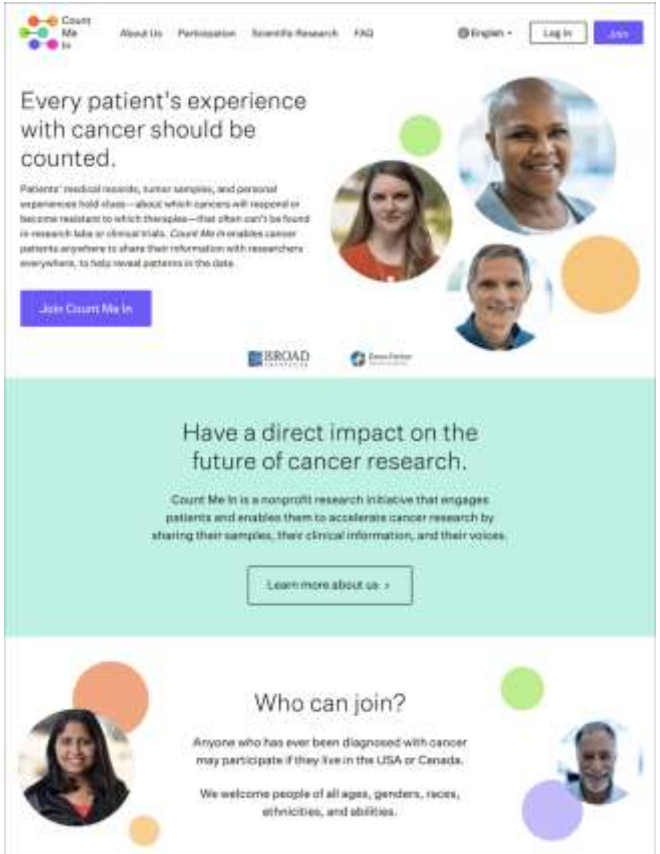
Leiomyosarcoma Project

Count
Me
In

Count Me In (CMI) is a nonprofit research initiative of the Broad Institute that engages with patients and enables them to accelerate cancer research by sharing their **samples**, their **clinical information**, and their **voices**.

The goal is to generate publicly available databases of clinical, genomic, molecular, and patient reported data in rare cancers to accelerate discoveries and the development of new treatment strategies.

Enrollment and consent are all done digitally via the Count Me In website.



Every patient's experience with cancer should be counted.

Patients' medical records, tumor samples, and personal experiences hold clues—about which cancers will respond or become resistant to which therapies—that often can't be found in research labs or clinical trials. *Count Me In* enables cancer patients anywhere to share their information with researchers everywhere, to help reveal patterns in the data.

Have a direct impact on the future of cancer research.

Count Me In is a nonprofit research initiative that engages patients and enables them to accelerate cancer research by sharing their samples, their clinical information, and their voices.

Who can join?

Anyone who has ever been diagnosed with cancer may participate if they live in the USA or Canada.

We welcome people of all ages, genders, races, ethnicities, and abilities.

JoinCountMeIn.org

Count Me In PE-CGS Center:
Osteosarcoma (OS) and Leiomyosarcoma (LMS)

BROAD INSTITUTE Dana-Farber Cancer Institute Boston Children's Hospital HARVARD MEDICAL SCHOOL Count Me In

- Leiomyosarcoma (LMS) and Osteosarcoma (OS) are both rare cancers each with approximately 2,000 or fewer cases per year in the United States
- Minimal improvement in survival or treatment-related morbidity in Osteosarcoma and Leiomyosarcoma – largely due to insufficient characterization of the genomic landscape
- Urgent need to generate a large, shared database of clinical and genomic data in OS and LMS
- Challenging to do this to date – because of rarity of these tumor types and other challenges in patient recruitment and the genomic characterization of these tumors

Study Objectives

1) Establish a **network of engaged pediatric and adult participants with OS and LMS** and co-create a shared database of clinical, genomic, molecular, and patient reported data to enable research.

2) Analyze clinically annotated **whole exome, whole transcriptome, and whole genome** data from tumors, germline, and cell-free DNA to elucidate the biology of OS/LMS and identify novel targets, markers of therapeutic response and resistance, prognostic indicators, and germline risk factors.

3) Optimize the **approach to direct patient engagement in cancer genomics** research with a particular focus on rural and minority participants as well as participants across a range of literacy levels, ages, and stages in development.

Our goal is to engage patients with OS and LMS across the US and Canada to generate a large publicly available database of clinical, genomic, molecular, and patient reported data.

OS Project Consents/Samples Received

Data as of 03/01/2024

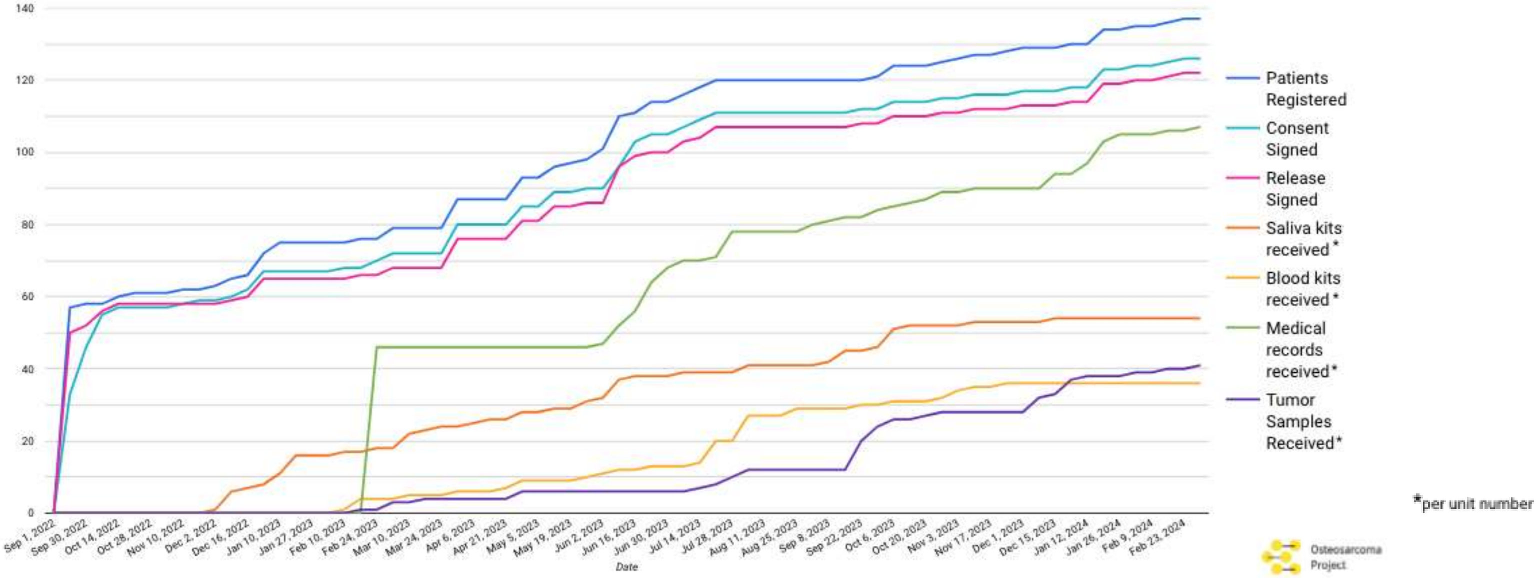
Metric	Value
Clicked "Count Me In"	137
Consent Form: Main Study	126
Consent Form: Tumor Shared Learnings	109
Consent Form: Normal DNA seq. w/ Invitae	28
Saliva Kits Received	54
Blood Kits Received	36
Medical Records Received*	107 sets / 77 pts.
Tumor Samples Received*	41 samples / 30 pts.

*For Medical Records Received and Tumor Samples Received, there is a larger number of medical records and tumor samples received, than there are patients for whom we've received these samples.

This is because we have (and frequently do) receive more than one medical record and/or tissue sample per participant.

OS Project Enrollment Curve

Data as of 03/01/2024



JoinCountMeIn.org

LMS Project Consents/Samples Received

Data as of 03/01/2024

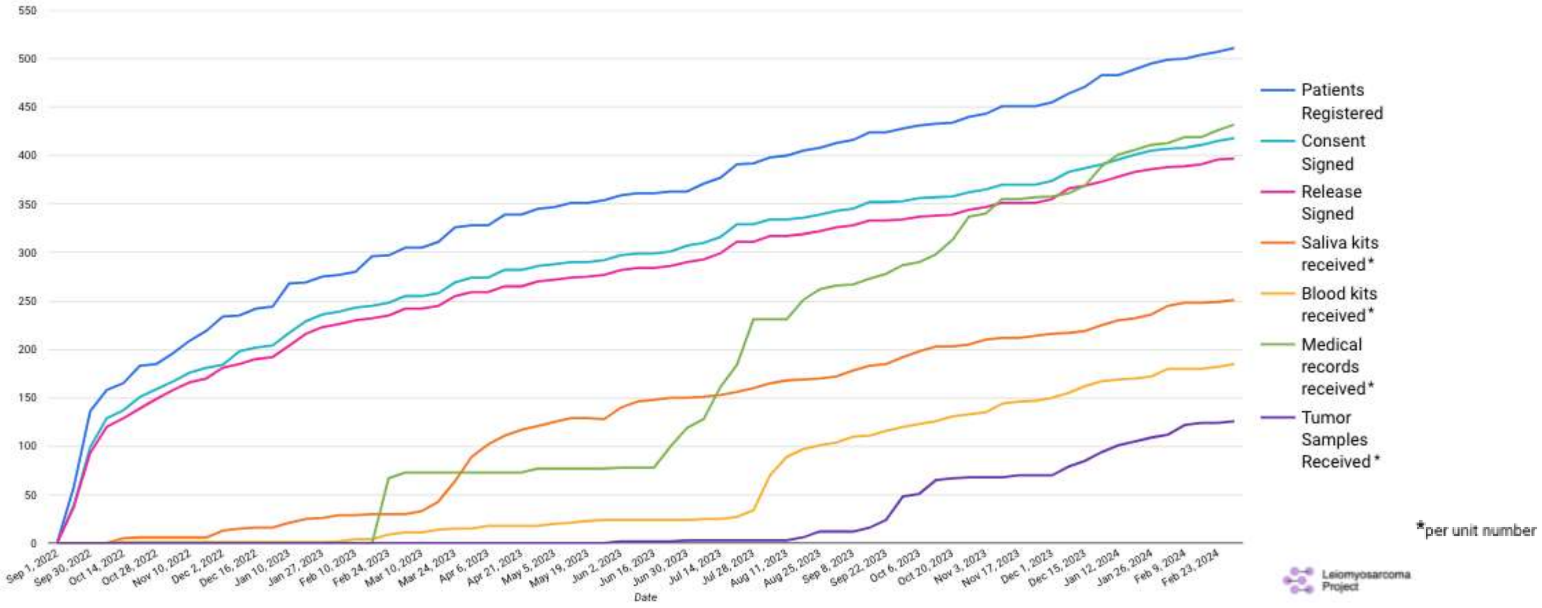
Metric	Value
Clicked "Count Me In"	511
Consent Form: Main Study	418
Consent Form: Tumor Shared Learnings	362
Consent Form: Normal DNA seq. w/ Invitae	105
Saliva Kits Received	251
Blood Kits Received	185
Medical Records Received*	432 sets / 266 pts.
Tumor Samples Received*	126 samples / 96 pts.

*For Medical Records Received and Tumor Samples Received, there is a larger number of medical records and tumor samples received, than there are patients for whom we've received these samples.

This is because we have (and frequently do) receive more than one medical record and/or tissue sample per participant.

LMS Project Enrollment Curve

Data as of 03/01/2024



JoinCountMeIn.org

Sharing the Word:

Together, the osteosarcoma community has the power to move research forward.

Osteosarcoma Project

Count Me In's patient-partnered research project helps to generate the most comprehensive osteosarcoma database to accelerate research and the development of new therapies.

You hold the key to unlocking future discoveries.

"What's exciting to me is that it's so easy to participate, because with rare cancers, there just aren't enough medical samples out there, so to be able to participate from anywhere in the country to help progress research is amazing."

Maeve
Osteosarcoma Project Patient

Kathryn
Sarcoma
Project Patient

If you or your child has ever been diagnosed with osteosarcoma, you can make an impact by sharing your samples, experience and access to medical records.

Join by completing these 4 easy steps:

Step 1
Provide consent and tell us where you've been treated.

Step 2
Answer questions about your cancer.

Step 3
Provide samples (we'll send you a kit.)

Step 4
Learn with us along the way!

Scan the QR today, and help change the future of osteosarcoma.
OSProject.org

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Juntos, la comunidad de osteosarcoma tiene el poder de impulsar la investigación del cáncer adelante.

Osteosarcoma Project

Count Me In es un proyecto de investigación que, junto con pacientes, ayuda a generar la más completa base de datos e información de osteosarcoma para acelerar la investigación y el desarrollo de nuevas terapias.

Usted tiene la clave para hacer futuros descubrimientos.

"Lo que me emociona es que es tan fácil de participar, porque con cánceres raros, simplemente no hay suficientes muestras médicas, poder participar desde cualquier lugar en el país para ayudar al progreso de la investigación es increíble."

Maeve
Paciente del Osteosarcoma Project

Kathryn
Sarcoma
Paciente del proyecto

Si usted o su hijo(a) alguna vez ha sido diagnosticado con osteosarcoma, usted puede hacer un impacto al compartir sus muestras, experiencia, y acceso a su historia clínica.

Únase completando estos 4 simples pasos:

Paso 1
Dé su consentimiento e indique dónde ha recibido tratamiento.

Paso 2
Responda preguntas sobre su cáncer.

Paso 3
Proporcione muestras (le enviaremos un kit).

Paso 4
Aprenda junto con nosotros!

Escanee el código QR hoy y ayude a cambiar el futuro del osteosarcoma.
OSProject.org

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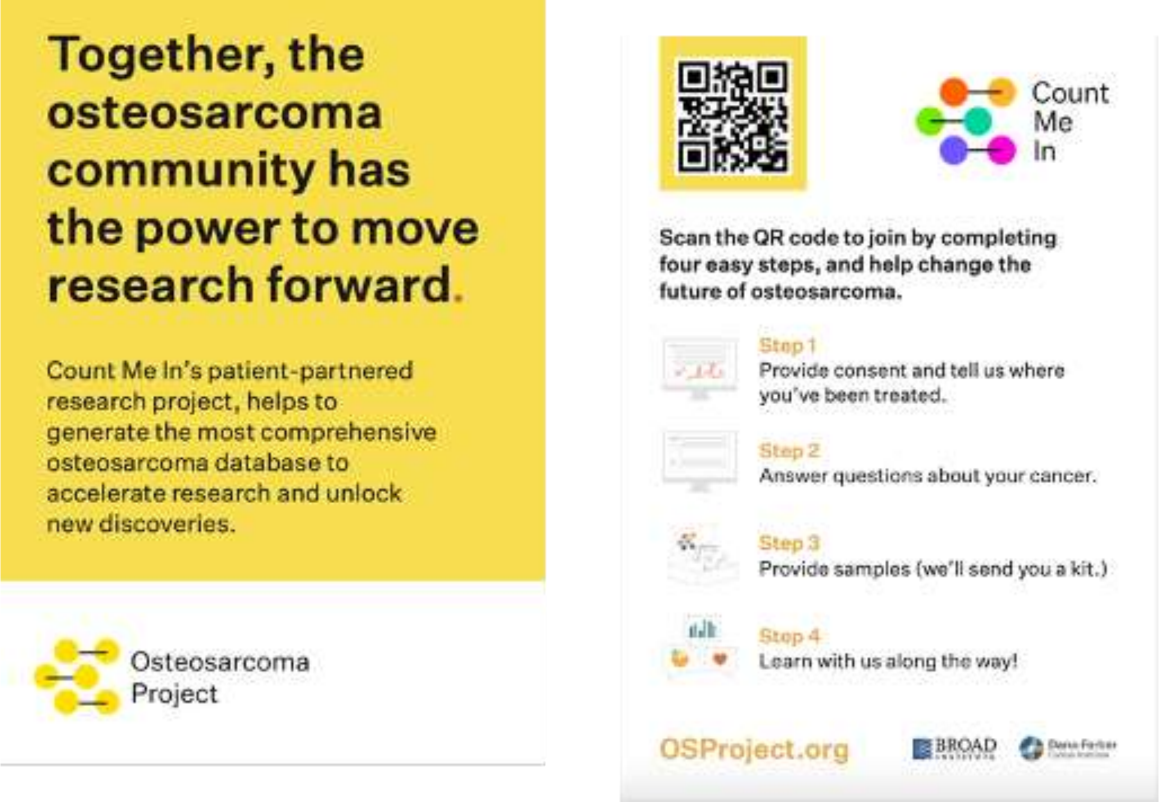
Dana-Farber Cancer Institute

8.5 x 11 Flyer

JoinCountMeIn.org



Together, the osteosarcoma community has the power to move research forward.

Count Me In's patient-partnered research project, helps to generate the most comprehensive osteosarcoma database to accelerate research and unlock new discoveries.

Osteosarcoma Project

Count Me In

Scan the QR code to join by completing four easy steps, and help change the future of osteosarcoma.

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OSProject.org

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5 x 7 Card

(Available in English and Spanish)

JoinCountMeIn.org

Have a direct impact on the future of leiomyosarcoma.

Leiomyosarcoma Project

Count Me In's patient-partnered research project helps to generate the most comprehensive leiomyosarcoma database to accelerate research and the development of new therapies.

You hold the key to unlocking future discoveries.

If you have ever been diagnosed with leiomyosarcoma, join a nationwide movement of patients to contribute your samples, your medical records, and your voice to leiomyosarcoma research.

Together, we can speed the development of future therapies.

Scan the QR today, and help change the future of leiomyosarcoma.

LMSProject.org

Join by completing these 4 easy steps:

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Step 2
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Step 3
Provide samples (we'll send you a kit.)

Step 4
Learn with us along the way!

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Ten un impacto directo en el futuro de Leiomiosarcoma.

Leiomyosarcoma Project

El proyecto de investigación en alianza con pacientes de Count Me In, ayuda a generar la base de datos más completa de leiomiosarcoma para impulsar las investigaciones y acceder a nuevas terapias.

Usted tiene la clave para hacer futuros descubrimientos.

Si alguna vez has recibido un diagnóstico de leiomiosarcoma, únete a una iniciativa con participación de pacientes a nivel nacional y aporta tus muestras, historias clínicas y experiencia a la investigación sobre el leiomiosarcoma.

Juntos, podemos acelerar el desarrollo de futuros tratamientos.

Escanee el codigo QR para unirse y cambiar el futuro del leiomiosarcoma.

LMSProject.org

Únase completando estos 4 simples pasos:

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Paso 4
¡Aprenda con nosotros!

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Have a direct impact on the future of leiomyosarcoma.

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5 x 7 Card

(Available in English and Spanish)

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How You Can Help:

Scan the QR code and complete the form to request materials shown earlier in this presentation.

Contact Us!

Please reach out to Project Manager Eirian Siegal-Botti at esiegalb@broadinstitute.org with any questions.

For any questions from patients, please direct them to our OS Project email inbox, info@osproject.org, or our LMS Project email inbox, info@lmsproject.org.

Check out our project websites!

- https://osproject.org/
- https://lmsproject.org/

If you would like to receive physical copies of our informational materials, please let us know!