BEACON SARCOMA

SUMMARY

thank you for taking part in this research study, your help and contribution was invaluable.

this study explored the experiences of children and young people who were sarcoma survivors, to learn more about what helped sarcoma survivors to be physically active.

we hope to use this information to help us develop, and improve, a physical activity support programme.

01 WHAT DID WE DO?

We interviewed 22 child, adolescent and young adult (CAYA) sarcoma survivors. These interviews included questions to help us identify and understand the challenges they faced and the things that helped them take part in physical activity.

02 WHAT DID WE FIND?

- For young people, getting back to being active often started with accepting that their body had changed and that physical activity might feel different than it did before cancer.
- Many young people needed time to rebuild their confidence in being active, especially after surgery. Learning new ways to move and adapt activities to suit their body helped them be active.
- Young people appreciated advice, resources, and encouragement that was matched to their age, interests, and physical abilities.

03 SO, WHAT DID WE DO NEXT?

- We then invited CAYA (and their parents if aged under 16) to attend workshops to help us focus on their preferences for support to be more physically active.
- We held four workshops: two with three young people and two with two teenagers and their parents.
- We also had two phone calls with young people to discuss these findings.

04 WHAT DID WE THEN FIND ?

In the workshops, the teenagers and young people decided together that:

- the physical activity support should help CAYA sarcoma survivors to take the first steps to being active again after treatment, especially in their own communities.
- the support should also create a community where young people with similar sarcoma experiences can share advice, learn from each other, and offer support.

05 WHAT NEXT?

- We are now sharing our findings with doctors, oncologists and physiotherapists who work with CAYA sarcoma survivors.
- As a result of your help in this study, we can improve the design of a physical activity support intervention, to try to make sure it can meet the needs and preferences of CAYA survivors of sarcoma.

Newcastle University
Sarcoma UK The bone & soft tissue cancer charity
NHS The Newcastle upon Tyne Hospitals NHS Foundation Trust
NHS Royal National Orthopaedic Hospital NHS Trust
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