

Co-creation of an integrative oncology app - building together from lived experience to address unmet support needs

Dr Nina Fuller-Shavel^{1,2}, Korina Karadimou¹, Dr Penny Kechagioglou^{1,3}

1 Oncio CIC, United Kingdom
2 Synthesis Clinic, United Kingdom
3 Coventry and Warwickshire Partnership NHS Trust, United Kingdom

Background

- Digital health solutions are increasingly being used in cancer care.
- Despite a proliferation of symptom tracker tools, there is a lack of freely available interactive and engaging apps supporting integrative cancer care.

Methods

- Using a cross-sectional design, an electronic survey aimed at adults with lived experience of cancer (personal experience + carers) was distributed via several channels:
 - three UK charities
 - multiple social media channels of the Oncio CIC (Community Interest Company)
 - panel members with lived experience and professional content contributors
 - three UK breast cancer outpatient hospital departments.
- The survey received **198 responses** over two weeks in February 2023 with all respondents completing the full survey (average time to completion = 6 min).

Results

- **Demographics**
 - over 90% of 198 respondents had personal experience of cancer with the rest being carers or family members
 - 26% in active treatment
 - 46% completed active treatment in the last 5 years
 - Age range 21-60+ with 88% in the 40-59 age group
 - 73% employed full or part-time, 11% retired
 - 95% of respondents were female or identified as female
 - 47% White and 50% White British, ethnic minority engagement 3%
- **45% of respondents received no advice on non-pharmacological approaches** to symptom control or quality of life support from their oncology team.

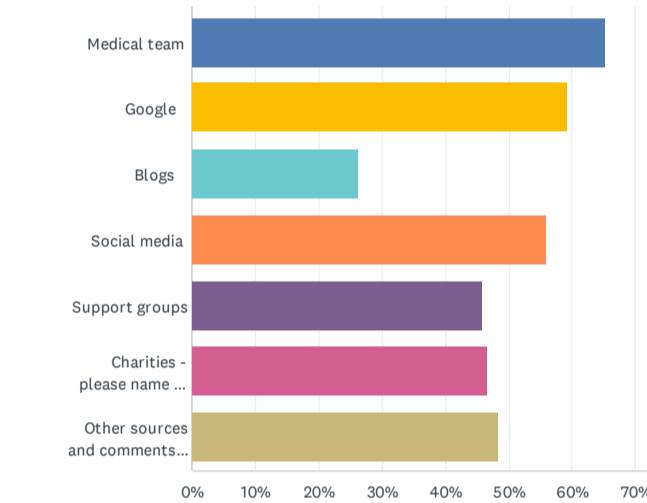
Almost **100%** of people with lived experience of cancer in our UK survey (n=198) would have liked **more support** with the most common areas highlighted being **nutrition, psychological and emotional wellbeing support, supplement use and complementary therapies.**

Only **18% were satisfied** with the tools and resources provided with **93% of respondents interested in an app** offering programmes with daily content and additional articles, video and audio resources. These findings illustrated the need for and informed the initial development of the Oncio app.

Topic/area of information need	% of respondents who received general advice	% of respondents who wanted additional advice	Gap of information supply vs need
Nutrition	17%	73%	56%
Physical activity	22%	50%	28%
Sleep support	6%	53%	47%
Stress management & emotional wellbeing	16%	71%	55%
Complementary therapies	10%	65%	55%
Safe use of supplements	0%	69%	69%

Results

- 66% of respondents mainly used technology to source relevant information with only 18% being satisfied with current tools/resources provided.
 - Most common apps used – NHS app (7%), Calm (6.5%), Fitbit (6%) and Headspace (5%)
- 93% of respondents interested in an app offering programmes with daily content and additional articles, video and audio resources (equal preference for different formats)
- Qualitative analysis of respondent comments highlighted common areas of need – understanding and sharing lived experiences ('me too'), treatment-related support to help manage side effects, post-treatment support (including managing weight gain and menopausal symptoms) and end of life preparation and care.



The top sources of health information were the **medical team (65%), Google (58%) and social media (53%).**

Voices of lived experience on needs:
"Trusted resources on complementary treatments and supplements to support my treatment plan to help with side effects"
Support after treatment "when you feel a bit like you've been pushed off a cliff...your body feels decades older than before your diagnosis, and you realise that life will never be quite the same again"

Conclusions and Clinical Implications

The Oncio app has been consciously co-designed with people affected by cancer, starting with the UK. While there are sources of sampling bias and further information from underserved populations is needed, the survey establishes a clear need for improved non-pharmacological support for people affected by cancer. Unmet information needs may be leading to a high reliance on sources with variable content quality. The Oncio app aims to focus on providing evidence-informed, interactive content across the key areas highlighted above.

Disclosure Information

No relevant disclosures