

EU Network of Youth Cancer Survivors (EU-CAYAS-NET)

Grant Agreement No. 101056918

Network Platform

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WP(s): WP2

Task(s): Task 2.1 Develop the Platform backend

Task 2.2 Establish the Platform design and architecture



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Version History

Version	Date	Description
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V0.1	2023-01-13	Draft reviewed
V1.0	2023-01-13	Final version submitted to EU4Health

Full Name	Short Name	Number	Role
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FUNDATIA YOUTH CANCER EUROPE	YCE	2	Beneficiary
SIOP EUROPE	SIOPE	3	Beneficiary
PANCARE	PANCARE	4	Beneficiary
PRINSES MAXIMA CENTRUM VOOR KINDERONCOLOGIE BV	PMC	5	Beneficiary
PAGALBOS ONKOLOGINIAMS LIGONIAMS ASOCIACIJA	POLA	6	Beneficiary
FUNDACIO PRIVADA PER A LA RECERCA I LA DOCENCIA SANT JOAN DE DEU	FSJD	7	Beneficiary
HOSPITAL SANT JOAN DE DEU	HSJD	7.1	Affiliated Entity
MEDIZINISCHE UNIVERSITAET WIEN	MUW	8	Beneficiary
PINTAIL LTD	PT	9	Beneficiary
SURVIVORS ÖSTERREICH - KINDER-KREBS-ÜBERLEBENDEN-INITIATIVE	SurvivorsAT	10	Associated Partner
Fondation d'Utilité Publique KickCancer	KickCancer	11	Associated Partner
Assosiation Heart for children with cancer	AHCC	14	Associated Partner
ASSOCIATION CHILDREN WITH ONCOHEMATOLOGIC DISEASES	ACOD	15	Associated Partner
Krijesnica - udruga za pomoc djeci i obiteljima suocenim s malignim bolestima	Krijesnica	16	Associated Partner
Spolecne k usmevu, z.s.	SkU	17	Associated Partner
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YouCan Cancer Support Network Ireland CLG	YouCan	21	Associated Partner
CanCare4Living (now Childhood Cancer Ireland)	CanCare4Living (now Childhood Cancer Ireland)	22	Associated Partner
CanTeen Ireland	CanTeen Ireland	23	Associated Partner
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	INT	24	Associated Partner
Vereniging Kinderkanker Nederland	VKN	25	Associated Partner
Fundacja Pani Ani	FPA	26	Associated Partner
Asociatia Obsteasca Filiala din Republica Moldova a Asociatiei Little People Romania	ALPMD	27	Associated Partner
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ASSOCIATION OF CHILDHOOD CANCER PARENT, GUARDIAN, CHILDREN AND FREINDS Chika Boca	CB&MladiCe	29	Associated Partner
"Zvoncica" Childhood Cancer Parent Organization	ZVONCICA	30	Associated Partner
Federación Española de Padres de Niños con Cáncer	FEPNC	31	Associated Partner
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Foundation Little knight	LITTLEKNIGHT_SI	34	Associated Partner
Kinderkrebs Schweiz	KinderkrebsCH	35	Associated Partner
Live Through This	LTT	36	Associated Partner
ON EST LA	ON EST LA	37	Associated Partner
ACREDITAR - Associação de pais e amigos de crianças com cancro	ACREDITAR	38	Associated Partner
EUROPEAN ONCOLOGY NURSING SOCIETY	EONS	39	Associated Partner
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Sano	Sano	42	Associated Partner

NETWORK PLATFORM

1	Executive Summary	5
2	Introduction & Background	5
3	Approach	5
4	Results	6
5	Impact & Conclusion	14
Figure 1	Snapshots of landing page	7
Figure 2	Snapshot of map with information about beneficiaries and Associated Partners	8
Figure 3	Snapshot of Contact Us page	8
Figure 4	Snapshot of newsletter subscription page.....	9
Figure 5	Snapshot of links to social media accounts/social media feeds	9
Figure 6	Snapshot of resources page	10
Figure 7	Snapshot of resources page	10
Figure 8	Snapshot of co-working and meeting space	11
Figure 9	Snapshot of video-conference facility.....	11
Figure 10	Snapshot of surveying feature	12
Figure 11	Snapshot of social media channels	12
Figure 12	Snapshot of landing page translation	13
Figure 13	Snapshot of Peer Support App information page	13

1 Executive Summary

D2.1 'Network Platform' explains the importance of the Network Platform as the catalyst for all the project activities and pre-requisite for numerous project tasks. The Network Platform is the face and the voice of the project – reflecting the needs, preferences and tone of the young cancer survivors – the driving force of the project. The report explains how survivorship organisations involved in the Network have come up with the concept, design and architecture for the Network Platform, as well as how it was created and tested. An overview of main features of the Network Platform is provided in graphic snapshots and explains the expected impact of the Network Platform and its relation with other tasks within the project, explaining why it is a central deliverable of the project.

2 Introduction & Background

The Network Platform is the catalyst for all the project activities, acting as the knowledge-hub and the resource centre for initiatives and best practices related to project tasks, as well as providing a co-working space for project team, affiliated organisations and youth cancer survivors, their families, healthcare professionals and policymakers. The launch of the publicly accessible Network Platform enables the start of numerous additional tasks of the project (for detailed info refer to Section 5). The Network Platform will play a central role in improving social networking and the links between young cancer survivors, caregivers, healthcare professionals and policymakers who are interested in the topics of Survivorship, Quality of Life, Adolescent and Young Adult Care, Equality Diversity and Inclusion.

Numerous tasks of the project will lead directly to the Network Platform and will either be used to provide content for the Network Platform or will help to generate content, collect feedback, facilitate discussions and analyse the metrics of audience engagement.

Impact and the uptake of the Network Platform will largely determine the success of the overall project as it is the face and the voice of the project – reflecting the needs, preferences and voices of the young cancer survivors – who are the driving force of the project.

3 Approach

As a first step, POLA drafted a technical specification for creating the Network Platform and approached several potential service providers.

In M1, a series of meetings was held with potential service providers aimed at identifying and assessing the feasibility and deployment of the state-of-the-art technological solution for hosting multilingual, content heavy and reactive platform, accessible via mobile and stationary devices. After consultation with CCI Europe and YCE, Mediapark (<https://mediapark.com/>) was selected as the service provider for creating the network platform by POLA. The agreed timelines for developing the Platform have been met, with a launch achieved in early Dec 2022 (M4).

The external services that were provided during M2 and M3 to develop the Platform included:

1. user experience guidance on vision and strategy of the Platform,
2. information architecture,
3. wireframes design,
4. project adjustments,
5. design works on:

- 5.1. concept design (home page, about us, events, search),
- 5.2. concept adjustment,
- 5.3. design adaptation to remaining pages (resources, articles, community, privacy policy),
- 5.4. additional elements (404 page, OG image, cookies pop-up),
- 5.5. design systems, hovers, forms, RTE, and
- 5.6. creation or responsive design and design adaptation adjustments.

The external services that were provided during M4 included the coding, responsive programming, and testing of Platform features across different platforms.

In M2, CCI Europe selected an external service provider (Karma Agency, <https://karma.agency/>) to create a social media strategy for the Platform. CCI Europe, together with the Karma Agency, co-organised a workshop on 24 Nov 2022 (M3) with project beneficiaries and Associated Partners to collect input for the social media strategy. The social media strategy will contribute to populating the Platform with the content and will be reflected in D2.2 'Social Media Metrics'.

Mediapark presented several alternative design options for the Knowledge Hub & Resource Centre, that were discussed by the project beneficiaries during the focus group meeting held by CCI Europe and Karma on 24 Nov 2022 (including representatives from YCE, CCI Europe, SIOP Europe, PanCare, PMC, HSJD, MUV and Associated Partners). During the meeting, the proposed design and architecture options were reviewed, focus group members provided their feedback and the final design option was selected.

POLA has coordinated the implementation of visuals, design and coding features with the external service provider on a daily basis. POLA has also purchased additional software licences for co-working space (e.g. WidgetBot for discord integration into online portal, Discord nitro for the video-conference facility, miro for brainstorming and project meeting sessions). In addition, POLA has purchased the domains of beatcancer.eu, youthcancersurvivors.eu and youthcancersurvivors.com and the hosting services for the duration of the project. POLA has created privacy policy, terms and conditions and cookies policy for the Network Platform and ensured their compliance with GDPR. The Platform was created with an intent to minimise the collection of any personal data and prioritised solutions that allow for opt-in anonymisation wherever possible.

YCE has monitored the implementation of selected design and visuals. CCI Europe has validated the final product.

The Network Platform was developed throughout M1-M4 and was launched on 28 Dec 2022.

4 Results

The Network Platform is live and accessible via the following interchangeable links: <https://beatcancer.eu/>, <https://youthcancersurvivors.eu/>, <https://youthcancersurvivors.com/>.

Snapshots from the Network Platform at launch are displayed below. The Platform will be continually updated and maintained over the duration of the project.

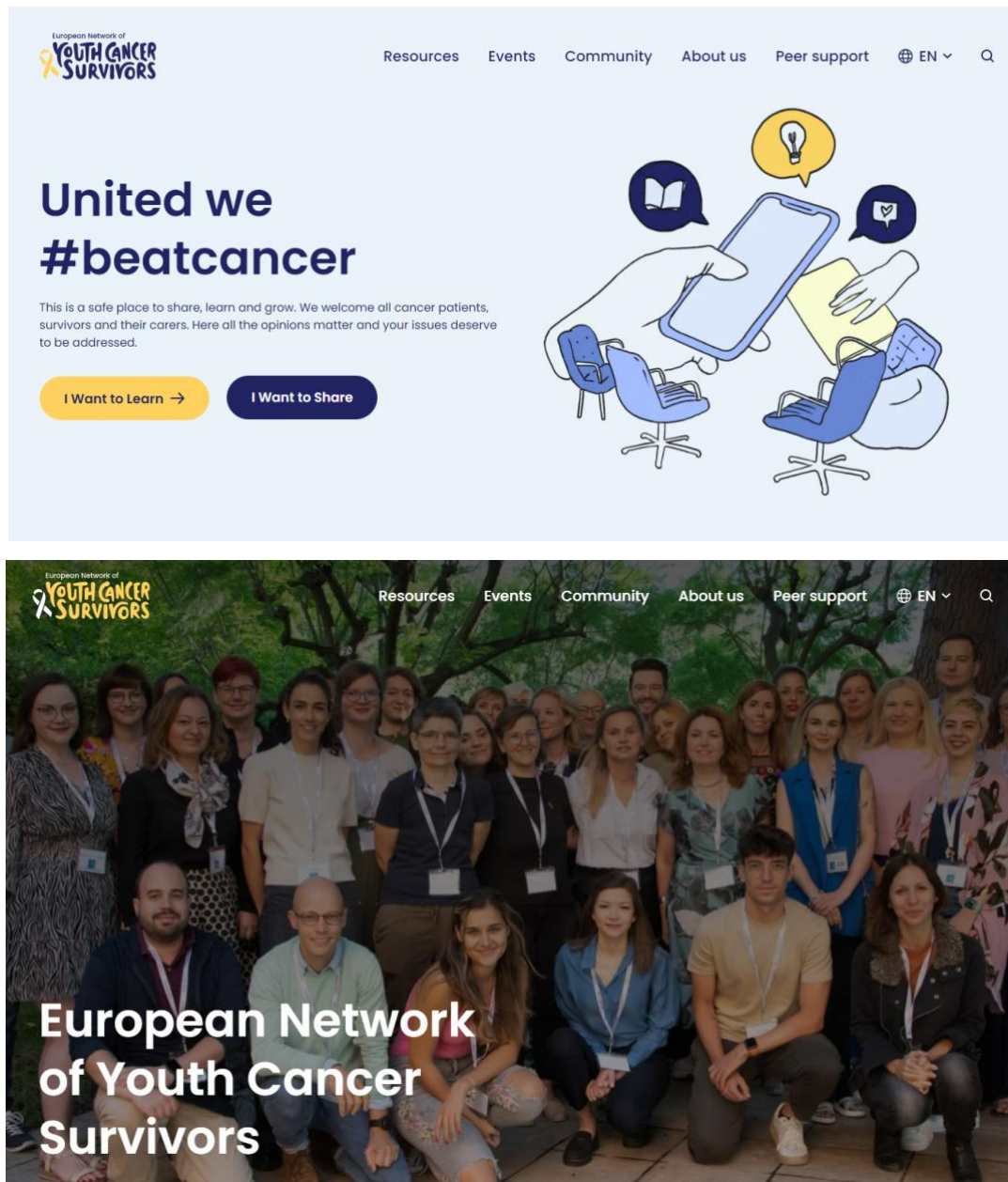


Figure 1 Snapshots of landing page

Countries participating in EU-CAYAS-NET project

Click on a country on the map to see the description of every contributing organisation



Figure 2 Snapshot of map with information about beneficiaries and Associated Partners

Contact us

If you do not find what you are looking for, have questions or want to collaborate, send us a message below

[f Facebook](#)
[@ Instagram](#)
[v YouTube](#)

Name*

Email*

Message

☐ I agree with [privacy policy](#), [terms and conditions](#), [cookies policy](#)

Send

Figure 3 Snapshot of Contact Us page

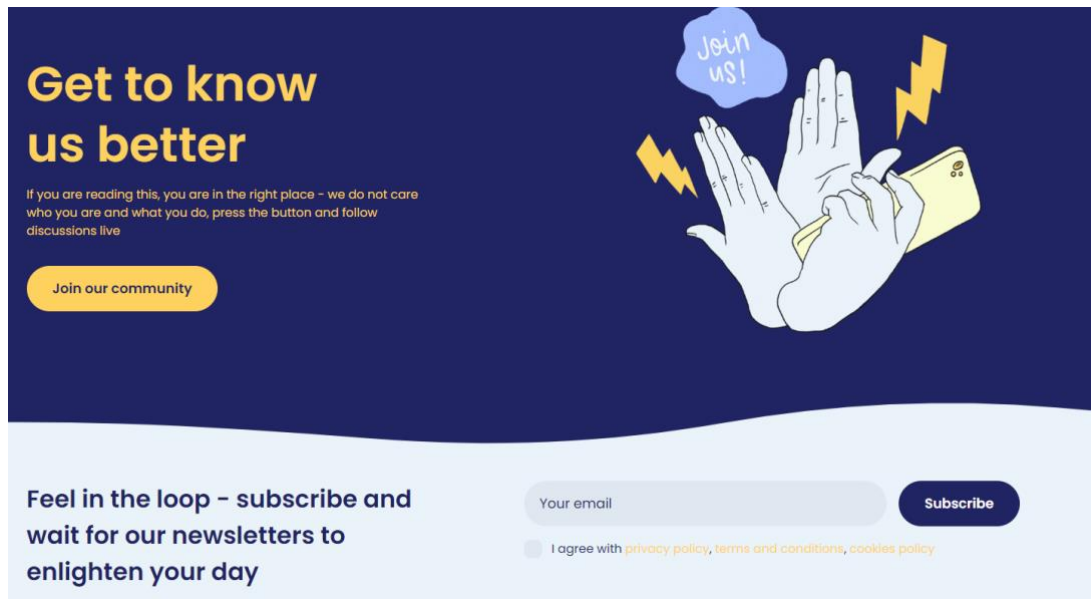


Figure 4 Snapshot of newsletter subscription page

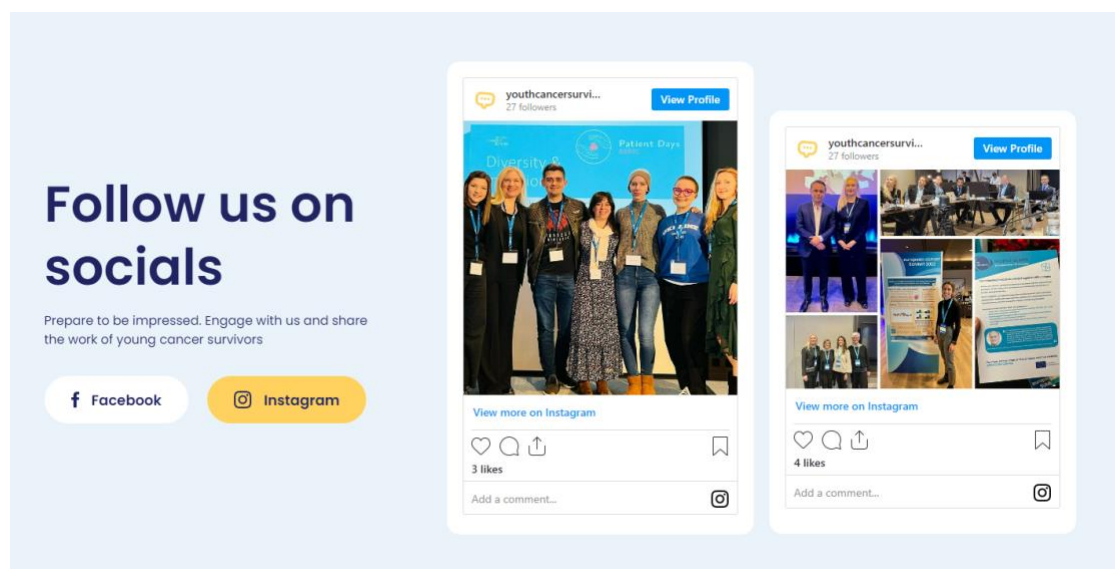


Figure 5 Snapshot of links to social media accounts/social media feeds

youth cancer



Resources: 8

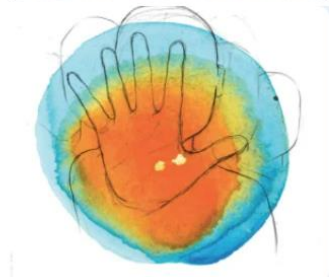


7TH NOVEMBER, 2018

The “Right to be Forgotten” Addressed in the European Parliament for the First Time

2018 video highlight from Youth Cancer Europe’s White Paper launch event at the European Parliament addressing the first of five key issues of the document: the Right to be Forgotten...

Policy Video



8TH DECEMBER, 2018

White Paper on the Needs of Young People Living with Cancer

Youth Cancer Europe’s White Paper sets out concrete steps and a timeline which allows the quantification of any real change its conclusions lead to, centred around five areas...

Policy Report

Figure 6 Snapshot of resources page

The Network Platform currently consists of:

- 1) A public resource centre with content that will be added to on a continuous basis over the project: <https://beatcancer.eu/resources/>

Topic

Cancer type

Resource type

Year 2022

Sort by Oldest first



2ND FEBRUARY, 2022

Report on Strengthening Europe in the Fight Against Cancer – Towards a Comprehensive and Coordinated Strategy

On 16 February 2022, the European Parliament adopted its final recommendations for a comprehensive and coordinated EU strategy to fight cancer. It focuses on cancer...

Policy Publication



1ST MARCH, 2022

A Europe for Children & Adolescents with Cancer: Position paper of the European paediatric cancer community

Cancer remains the first cause of death by disease in Europe in children older than 1 year - more than 35,000 cases are diagnosed and over 6,000 young patients die annually

Policy Report

Figure 7 Snapshot of resources page

- 2) a virtual co-working and meeting space, with public areas and internal project co-working areas: <https://beatcancer.eu/community/>

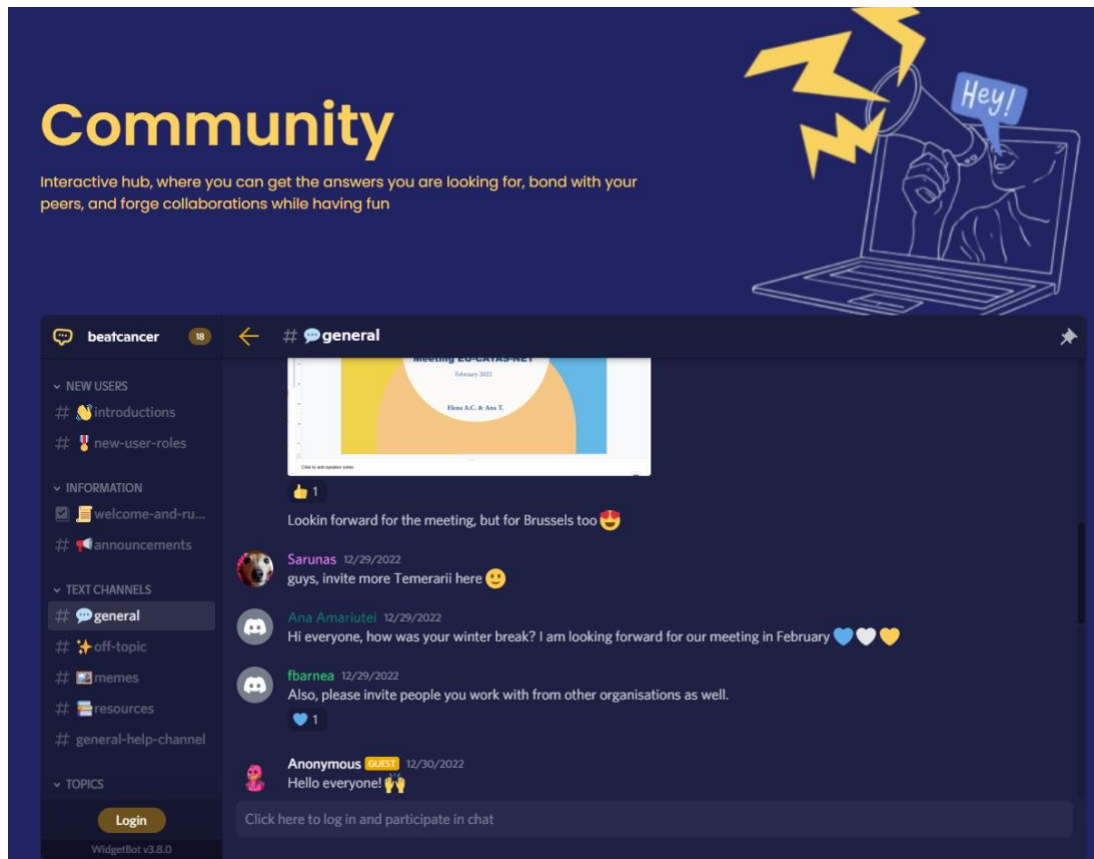


Figure 8 Snapshot of co-working and meeting space

- 3) an embedded video-conference facility (accessible via dedicated Discord channels)

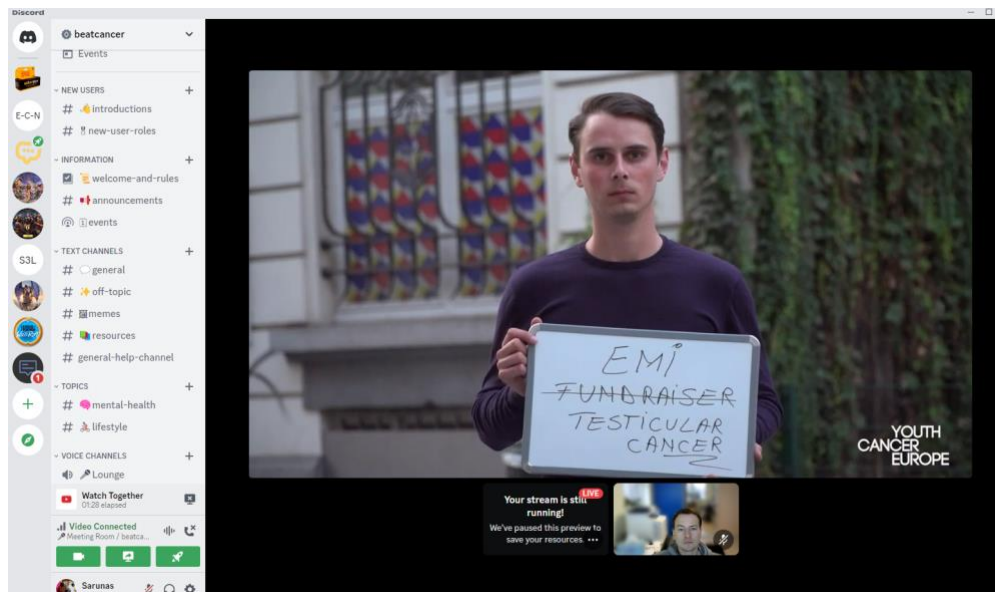


Figure 9 Snapshot of video-conference facility

- 4) a surveying feature, customisable via a portal admin panel,

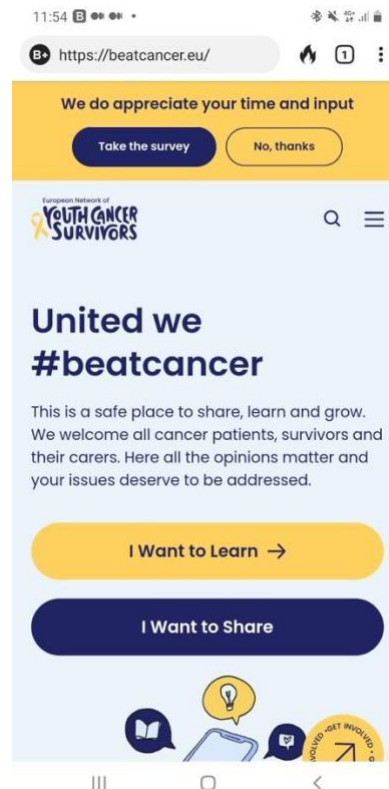


Figure 10 Snapshot of surveying feature

- 1) social media accounts (Facebook, @youthcancersurvivors (<https://www.facebook.com/YouthCancerEurope>; Instagram, @youthcancersurvivors, link: <https://www.instagram.com/youthcancersurvivors/>; Youtube channel @youthcancersurvivors, <https://www.youtube.com/@youthcancersurvivors>)¹.

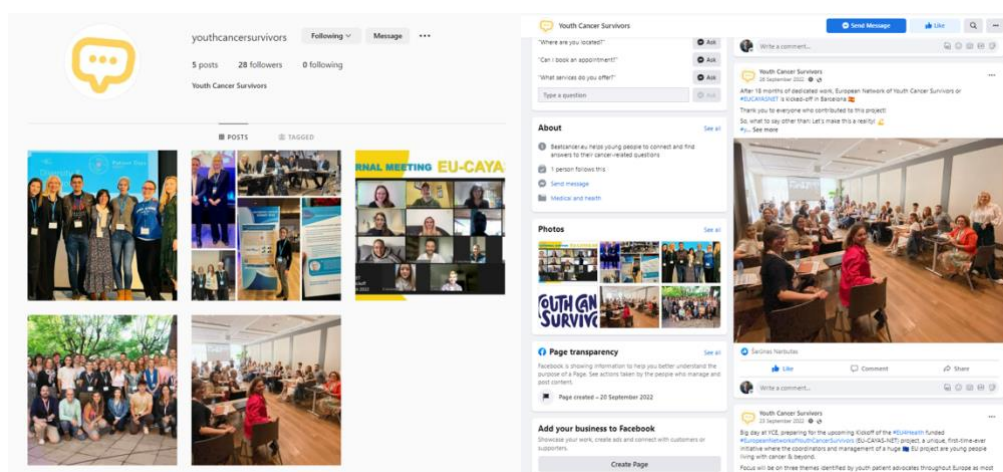


Figure 11 Snapshot of social media channels

¹ In line with the project plan, videos will be available later via Tasks 2.4 and 2.5.

The Network Platform is available in English (with embedded automatic translations in 24 EU official languages). 8 of the languages have been written / translated by native speaking professionals, namely: English, French, Spanish, Italian, German, Dutch, Bosnian-Serbo-Croatian and Lithuanian.

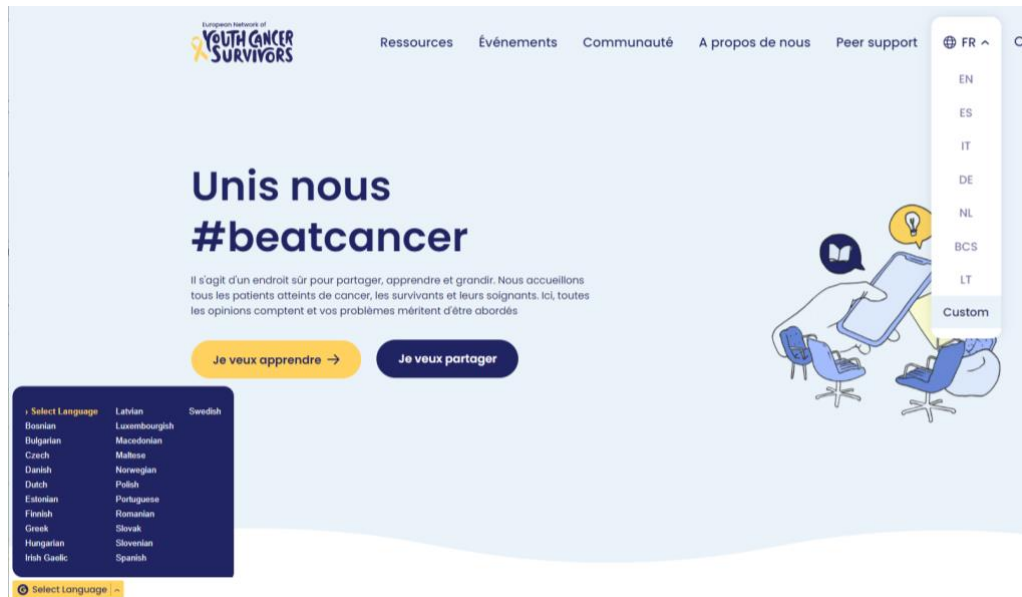


Figure 12 Snapshot of landing page translation

Integration with a peer-support app (task 2.6.) is scheduled to launch by M16.

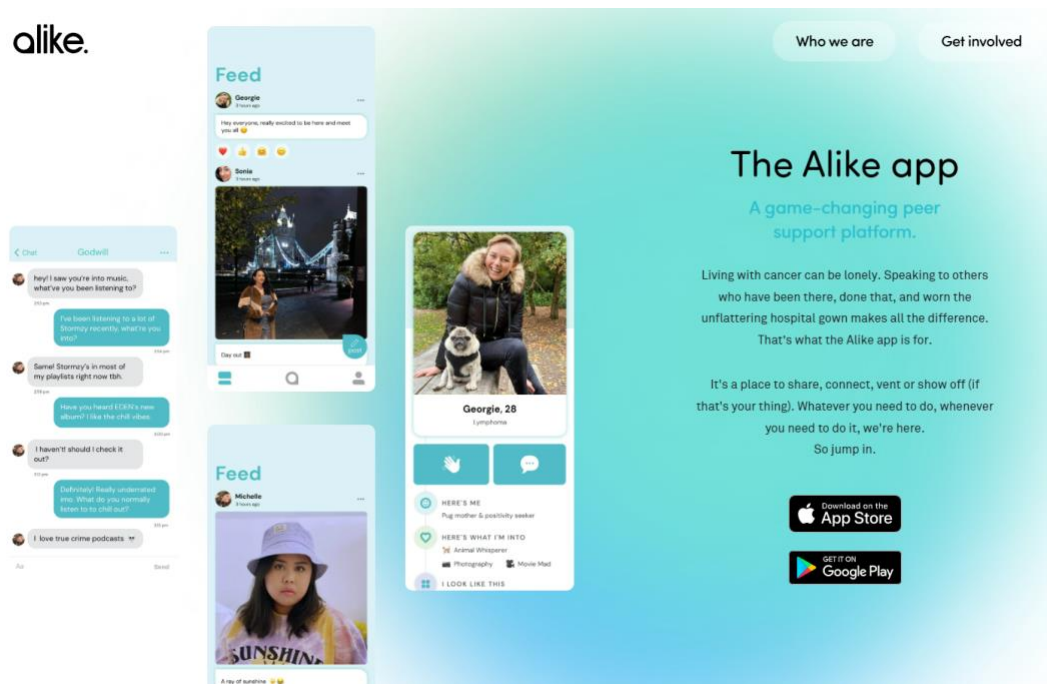


Figure 13 Snapshot of Peer Support App information page

5 Impact & Conclusion

This report describes the actions that were taken by the project beneficiaries in creating the Network Platform and provides the snapshot of the available features. The Network Platform is a central deliverable of the project and is a prerequisite to commence other numerous tasks within the project.

Launch of the Network Platform enables the network participants to share challenges, best practice and knowledge with each other through social networking and virtual co-working facilitated by a multilingual platform with an embedded video-conference facility to support virtual events. The Network Platform is created by young cancer survivors and is first tailoring their needs; however, it also invites participation of the families of the survivors, healthcare professionals and policymakers (who are also part of the project consortium and / or are involved in various tasks).

The “Contact Us” form will also allow to forge new links with young cancer survivors, their families or healthcare professionals throughout the duration of the project.

The features of the Network Platform separately, as well as jointly, provide a forum where the voice of the survivor leads the conversation about what is needed for healthy survivorship.

The “Resources” section of the Network Platform is freely accessible and is continuously populated with comprehensive content on existing knowledge and best practice for issues related to survivorship. An on-going collection of relevant resources will include relevant EU initiatives, including initiatives of Europe’s Beating Cancer Plan and will be uploaded and / or reference in the Network Platform.

The Network Platform will enable the hosting of a series of webinars, online events, brainstorming sessions, results of the discussion outcomes, policy papers and will be made publicly available and promoted to national and international cancer survivor organisations.

Later in the project, the Network Platform will include content from the thematic working packages (WP3 - WP5) and the engagement with the content will be tracked via analytics to measure impact on various metrics (related to D2.2).

Creation of the Network Platform marks the launch of numerous tasks, including:

- Task 2.4 Populate the Platform with content from WPs 3-5,
- Task 2.5 Identify and include existing resources on the Platform,
- Task 2.6 Integrate app for peer-support,
- Task 2.7 Adapting Platform content to social media accounts,
- Task 2.8 Organising, creating, disseminating webinars,
- Task 5.3 Online survey of participants from minority groups,
- Task 5.4 EDI practises Survey, and
- Task 6.4 Dissemination activities.