

Development of the STRONG-AYA federated learning-based adolescent and young adult cancer information portal: a co-creation process with adolescents and young adults with lived experience of cancer

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Abstract

Background: Adolescent and young adult (AYA) cancer represents a unique sub-domain in oncology, as AYAs experience cancer in a starkly different way from children, and older adults. The diverse and complex needs of AYAs result in an increasing impact and burden upon individuals and society. Nevertheless, widely accessible information and data insights are lacking for AYA stakeholders. In part, this is because widespread dissemination of such information is difficult and confined to local regions. Federated learning (FL) enables large-scale multi-centre data analysis without individual-level information disclosure. The STRONG-AYA Initiative combines precisely these components by setting up a FL-ecosystem including a vast amount of AYA cancer relevant data. Such developments present promising opportunities to tackle issues such as data availability and timeliness, creating a rich information landscape of AYA cancer for its diverse stakeholders.

Objective: To harness the opportunities introduced by FL we designed a FL-based AYA cancer information portal, aiming to transform AYA health information dissemination across the AYA landscape.

Methods: We described the portal's setting and variety of target audiences (stakeholder groups) for an AYA cancer portal, based on a consortium-wide consultation. With representatives of these stakeholder groups, we conducted unstructured interviews to obtain an initial concept of the requirements of this portal. The portal was designed to meet their requirements in bi-weekly iterative co-creation events between an AYA with lived experience and a researcher. The design was then evaluated using a think-aloud method, by a larger group of AYAs with lived experience and healthcare professionals. Finally, we developed a simplified proof-of-concept of our portal.

Results: Key stakeholders, including AYAs, and healthcare professionals, expressed a strong interest in an AYA cancer information portal. They acknowledged the benefits of harnessing FL insights and the specific opportunities provided by our FL methods. Our initial designs were well received but improvements were highlighted in information findability, usage guidance, and textual understandability. In our final version, reviewers felt their voices were heard and evaluated the resulting portal

favourably. They did however raise remaining concerns about the need for extensive continuous quantitative user experience testing and associated adaptations and updates required throughout the portal's lifetime. Our proof-of-concept lastly demonstrated it was possible to: extract relevant information from the STRONG-AYA FL-infrastructure without sacrificing data privacy, retrieve up-to-date information in an automated yet curated manner, and display analytical findings in a user-friendly manner.

Conclusions: By means of co-creation, we designed an AYA-specific cancer information portal, that was welcomed by stakeholders, and regarded as user-friendly, balanced in its design, and utilising the strengths of STRONG-AYA's FL-ecosystem. Simultaneously, we demonstrated that the realisation of such a FL-based portal is feasible using existing infrastructure.

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Title:

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Abstract (JMIR: 435 of 450 words)

Background

Adolescent and young adult (AYA) cancer represents a unique sub-domain in oncology, as AYAs experience cancer in a starkly different way from children, and older adults. The diverse and complex needs of AYAs result in an increasing impact and burden upon individuals and society. Nevertheless, widely accessible information and data insights are lacking for AYA stakeholders. In part, this is because widespread dissemination of such information is difficult and confined to local regions. Federated learning (FL) enables large-scale multi-centre data analysis without individual-level information disclosure. The STRONG-AYA Initiative combines precisely these components by setting up a FL-ecosystem including a vast amount of AYA cancer relevant data. Such developments present promising opportunities to tackle issues such as data availability and timeliness, creating a rich information landscape of AYA cancer for its diverse stakeholders.

Objective: To harness the opportunities introduced by FL we designed a FL-based AYA cancer information portal, aiming to transform AYA health information dissemination across the AYA landscape.

Methods

We described the portal's setting and variety of target audiences (stakeholder groups) for an AYA cancer portal, based on a consortium-wide consultation. With representatives of these stakeholder groups, we conducted unstructured interviews to obtain an initial concept of the requirements of this portal. The portal was designed to meet their requirements in bi-weekly iterative co-creation events between an AYA with lived experience and a researcher. The design was then evaluated using a think-aloud method, by a larger group of AYAs with lived experience and healthcare professionals. Finally, we developed a simplified proof-of-concept of our portal.

Results

Key stakeholders, including AYAs, and healthcare professionals, expressed a strong interest in an AYA cancer information portal. They acknowledged the benefits of harnessing FL insights and the specific opportunities provided by our FL methods. Our initial designs were well received but improvements were highlighted in information findability, usage guidance, and textual understandability. In our final version, reviewers felt their voices were heard and evaluated the resulting portal favourably. They did however raise remaining concerns about the need for extensive continuous quantitative user experience testing and associated adaptations and updates required throughout the portal's lifetime. Our proof-of-concept lastly demonstrated it was possible to: extract relevant information from the STRONG-AYA FL-infrastructure without sacrificing data privacy, retrieve up-to-date information in an automated yet curated manner, and display analytical findings in a user-friendly manner.

Conclusion

By means of co-creation, we designed an AYA-specific cancer information portal, that was welcomed by stakeholders, and regarded as user-friendly, balanced in its design, and utilising the strengths of STRONG-AYA's FL-ecosystem. Simultaneously, we demonstrated that the realisation of such a FL-based portal is feasible using existing infrastructure.

Introduction

Adolescent and Young Adult (AYA) cancer is distinct from paediatric and older adult cancer. AYAs, defined as individuals aged 15 to 39, experience cancer in unique ways due to their disease and treatment, impacting age-related milestones. AYAs are a developing cohort – they often partake in education, face critical early-career decisions, and encounter momentous questions regarding achieving independence, forging their own social networks, developing their own family or entering parenthood, both in terms of possibly having children and caring for children. These challenges are compounded by the many life-years lived with the consequences of cancer and its treatments, challenges which are often differently or substantially less relevant for cancer populations older than the AYA age^{1,2}. Therewith, insights from paediatric and older adult cancer often do not address AYAs' specific needs^{1,3,4}.

Despite comprising less than 7 per cent of all cancer diagnoses worldwide², AYA cancers can be a significant societal burden. This is partly due to that distinctiveness of the AYA life phase and the extensive number of years lived post-cancer with potential disabilities^{1,2}. Some countries, such as Denmark⁵ and the Netherlands⁶, have developed dedicated AYA resources and platforms with local information to support AYAs but have limited utility elsewhere. Therefore, increasing the widespread analysis of high-quality AYA cancer data and converting that into accessible information can potentially better inform – and empower – patients^{7,8}; it can also improve local and international AYA-specific care systems, treatment, and outcomes through the provision of an accurate and up-to-date evidence-base for clinical and policy decision-making.

Summarising such health-related information across institutions and especially nations is frequently impeded by data protection and sharing laws, as well as concerns regarding feasibility and privacy⁹. However, pooling findings from multiple locations is imperative to generating powerful data-driven evidence on rare diseases such as AYA cancers. Consequently, health-related analyses are often only available based on local-level data. The scientific literature, often confined behind paywalls, is

neither available to wider audiences nor timely – including for people who contributed their personal data. This is due to embargoes related to data agreements, collating and cleaning, analysing, publishing, and disseminating processes.

The recent advent of the privacy enhancing technology called federated learning (FL)¹⁰ and the Personal Health Train paradigm¹¹ offer an alternative way to handling data. They are founded on the principle of sharing statistical abstractions of data (e.g. descriptive statistics or epidemiological models) rather than the data itself, thereby providing strong confidential protection inherent within the methodological design. Building on this principle, FL does not require sharing individual-level data, allowing data to remain distributed and safeguarded in its local settings. Through a dedicated FL-ecosystem, data can thus be analysed without individual-level data disclosure, concurrently giving FL-managed data a potentially different lifecycle compared to data collected in a single central location. Information shared through FL can be of arbitrary complexity, ranging from complex artificial intelligence applications to summary statistics, and therewith holding great potential for AYA cancer.

Acknowledging the AYA-specific information needs and the opportunity that FL provides, The STRONG-AYA Initiative¹² is establishing a pan-European FL-ecosystem to help address AYA specific questions. STRONG-AYA aims to improve healthcare services, research, and outcomes for AYAs with cancer, by bringing together an international multi-disciplinary consortium across seven European countries and multiple groups of stakeholders: academic research organisations, clinical partners, policymakers, individuals with lived experience and patient organisations. STRONG-AYA's pan-European ecosystem enables AYA care and research to benefit from the collection and joint analysis of clinical and patient-reported data, fostering wider collaboration among all relevant stakeholders. Therewith, STRONG-AYA has a unique ecosystem for summarising and publicising evidence-based AYA cancer insights.

However, FL-ecosystems provide technical solutions with predominantly technical implementations,

primarily offering methodologies that enable questions (i.e. data analyses) to be sent to multiple data stations, which then return answers based on locally stored data. FL system outputs therewith typically are not cognitively accessible by the broader and non-scientific public. This is apparent when comparing healthcare information dissemination methods: public-friendly resources like leaflets (e.g. 'The Decision Helper'¹³), and online platforms (e.g. Cancer Research UK¹⁴) contrast sharply with typical FL analyses outputs¹⁵, that are less accessible to those without specialised knowledge. Media that are more cognitively accessible have specific benefits and challenges, with suitability varying by setting and stakeholders¹⁶. For instance, a leaflet provides many people with graspable information that they can re-consult when they need to, yet it is constrained by time and location. Whereas an online portal can more easily be kept up to date and provides information access regardless of location, at cost of requiring a higher degree of digital literacy.

To leverage STRONG-AYA's vast amount of data, stakeholder-driven use cases are paramount to the FL infrastructure, ranging from post-treatment survival rates to the proportion of AYA cancer patients experiencing psychological problems during and after treatment. Clearly defined use cases (examples of questions and analyses) enable the creation of evidence-based summaries from multiple locations without sharing individual data, making insights safer, faster, and more accessible than traditional methods. Through making such use cases multi-stakeholder-driven, the STRONG-AYA ecosystem can also build data solidarity by providing a timely benefit of their own choosing, for the AYA who chose to contribute their data. This can create benefits of data contribution that are privacy respecting, personalised, relevant, swiftly realised, and in an accessible information style.

Recognising the opportunity that STRONG-AYA presents to address challenges like data timeliness and AYA cancers' regional dispersion – due to rarity, an online FL-based AYA cancer information portal emerges as a promising approach to tackle these issues. To leverage this opportunity and address the need for accessible information, we aimed to design a stakeholder-tailored portal. We achieved this by first identifying the information needs of various stakeholders and then developing a

detailed design through an iterative co-creation process involving AYAs with lived experience and researchers, following an established design cycle.

Methodology

Setting of the portal

The STRONG-AYA Initiative is establishing a pan-European ecosystem harbouring data from 7 hospitals across 5 countries¹². For this, STRONG-AYA uses the Vantage6 FL-infrastructure^{17,18}, which provides an interface for users to interact with and visualise aggregated information. However, given the inherent technical complexities of federated learning, users not only require a substantial level of digital literacy, but they also require a form of ‘direct’ access to the federated infrastructure – this is required due to the design of the Vantage6 interface and the flexibility it provides. Such widespread access may introduce overly permissive and even lax data access to the public, which should be minimised for sensitive personal health data.

Identifying stakeholders

Within the STRONG-AYA consortium, our committee for coordination (CfC)¹⁹, identified five core stakeholder groups: AYAs and their confidantes (i.e. caregivers, significant others, and any individuals they trust), healthcare professionals (HCPs), policymakers, private parties (such as insurance companies), and scientific researchers. The reason for their inclusion varied, from personal interest, to hoped-for facilitation of policymaking and broader stakeholder engagement, all of which are summarised in Table 1. While the current interface for accessing the federated infrastructure requires 'direct' access, we found that this approach can raise concern regarding usage by certain stakeholders. Specifically, we argue that it may not be appropriate or desirable for all stakeholders to have such access due to the increased risk of misinterpretation (e.g. ‘comparing apples with oranges’), the need for self-preservation (i.e. protecting against undue alarm from misleading or atypical data), and – unintentional – misuse, particularly concerning data protection and privacy. Therefore, we structured the appropriateness of 'direct' federated infrastructure access as either low

or high based on the stakeholders' potential motives for access, as summarised in Table 1.

Based on this overview, we concluded that there is a distinct need for a platform that can bring health-related AYA cancer insights from within the STRONG-AYA ecosystem to stakeholders in underserved regions, those affected by rare cancer subtypes, and professionals seeking large-scale comparative data – groups that are poorly supported by existing resources.

Understanding what these stakeholders seek and require in a portal or interface is crucial to define appropriateness, and scale for uptake and usability. For this we adhered to a common iterative user experience design cycle consisting of *Requirement gathering, alternative designs, prototyping, and evaluation*, and in this cycle we strived to integrate various concepts of the design thinking framework²⁰.

Stakeholder	Assumed Interest	Access rationales	Existing infrastructure access suitability
AYAs (and confidantes)	Personal interest	Application complexity Application latency Data equity Data protection Risk in (mis-) interpretation Self-preservation	Low
Healthcare professionals*	AYA cancer care-needs	Application complexity Application latency 'Business' intelligence Data protection Evidence-based care	Low
Private parties (e.g. insurance companies)	Budgeting and financing	Application complexity Business intelligence Data protection Risk in (mis-) interpretation Risk of misuse	Low to high
Policymakers	Policy making and commissioning	Application complexity Application latency Business intelligence Data protection Risk in (mis-) interpretation Risk of misuse	Low
Scientific researchers	Data exploration and analyses	Data protection Scientific freedom	High

Table 1: Overview of stakeholders, their assumed interest, and access needs for an AYA cancer information portal leveraging a federated learning infrastructure. *Note that in this context healthcare professionals are healthcare professionals that exclusively work within healthcare, and do not perform any form of scientific research.

Requirement gathering

Organisational requirements

The STRONG-AYA CfC oversees the ecosystems organisational requirements, including defining member responsibilities, criteria for new members, and ensuring data consistency and sustainability. Comprising leaders from local and national ecosystems and patient advocates, the CfC has agreed that a public-facing portal based on the STRONG-AYA ecosystem can only be used by individuals accepting the mutually agreed terms and conditions. The portal should operate with user-specific permissions based on internally defined access-control profiles, which accommodate the varying needs of various stakeholders. For example, some profiles may grant access to specific use cases, while others restrict it. All insights are limited to prospectively approved, well-defined use cases.

Stakeholder requirements

To obtain an initial concept of an AYA cancer portal's requirements, we conducted three unstructured interviews with five AYAs cancer experts within the STRONG-AYA consortium, whose expertise spanned the perspectives of AYAs and their confidantes, healthcare professionals (HCPs), policymakers, and scientific researchers. Each of these stakeholder archetypes Table 1 was represented – through professional or advocacy-based ties – within digitally recorded interviews which were conducted online. The consulted experts gave informed consent for these interviews to be pursued and recorded, and were diverse in sex, age, nationality, and experience with AYA cancer. From open coding of interview recordings we developed personas that describe general goals for the use of an AYA cancer information portal and its prerequisites. These personas were then used to develop a set of minimal requirements for the portal.

Alternative designs

An 'alternative design' phase in our portal development involved crude review and analysis of leading existing medical data portals, general high-traffic websites and web-shops, including The Global Cancer Observatory²¹, Santeon Patient Like me²², European Cancer Pulse²³, and the Decision

Helper by Stine R. Søndergaard¹³, between January and July 2024. We informally examined the amount of information shown, number of interactions, filter presentation, and degree of modifiability of information selected by others. We inspected variations in usability cues such as affordance, signifiers, and feedback of inspected sources.

Prototype design

The requirements elicited by initial interviews and analysis of designs were applied to develop a prototype in Adobe Xd, by iterative co-creation between T.D. and J.H. In this process, T.D. is an AYA patient advocate with lived experience who is also an expert in both user interface and experience design, whereas J.H. is a scientific researcher who described the requirements and worked on developing the prototype. For co-creation, T.D. and J.H. had bi-weekly interactions when iterations of the prototype were reviewed and refined, to address stakeholders' requirements. During these interactions J.H. presented a new iteration that was then reviewed by T.D., who provided feedback for J.H. to improve the prototype for the following iteration. With every iteration JH also (re-)analysed existing resources from the alternative designs phase.

Evaluation

A near-final prototype draft was presented to a partner patient organisation, Youth Cancer Europe (YCE), including a scientific researcher and 5 AYAs with lived experience with diverse educational backgrounds and from diverse European countries, balanced by gender and cancer history ranging from 3 to over 15 years. Online, this group was first guided through the prototype and its features, followed by an open discussion defining ways to improve the prototype in a semi-think aloud manner, guided by the evaluation of the *MyChristie-MyHealth* app²⁴. The guiding questions can be found in .

Further insights were incorporated by J.H. (in coordination with T.D.) and three of the five initially consulted patient advocates were presented with the final prototype as a last iteration of our co-creation. A schematic overview of our entire design process can be found in Error: Reference source

not found.

Alongside this, an online AYA and HCP workshop gathered additional feedback from stakeholders outside STRONG-AYA (10 HCPs, 1 AYA with lived experience, and 1 researcher). AYAs and HCPs were invited through a snowball process across AYA-focused clinical groups. The candidate portal design, use cases, data analyses, and displays were presented, and participants were given access to navigate the prototype using Adobe Xd's sharing functionality. Participants had time to explore the prototype, and feedback was sought on aspects including the overall look, feel, and perceived usability of the portal. Participants were prompted to comment on priorities for improving the next design, concerns about presentation style, and envisioned uses of the portal in their roles.

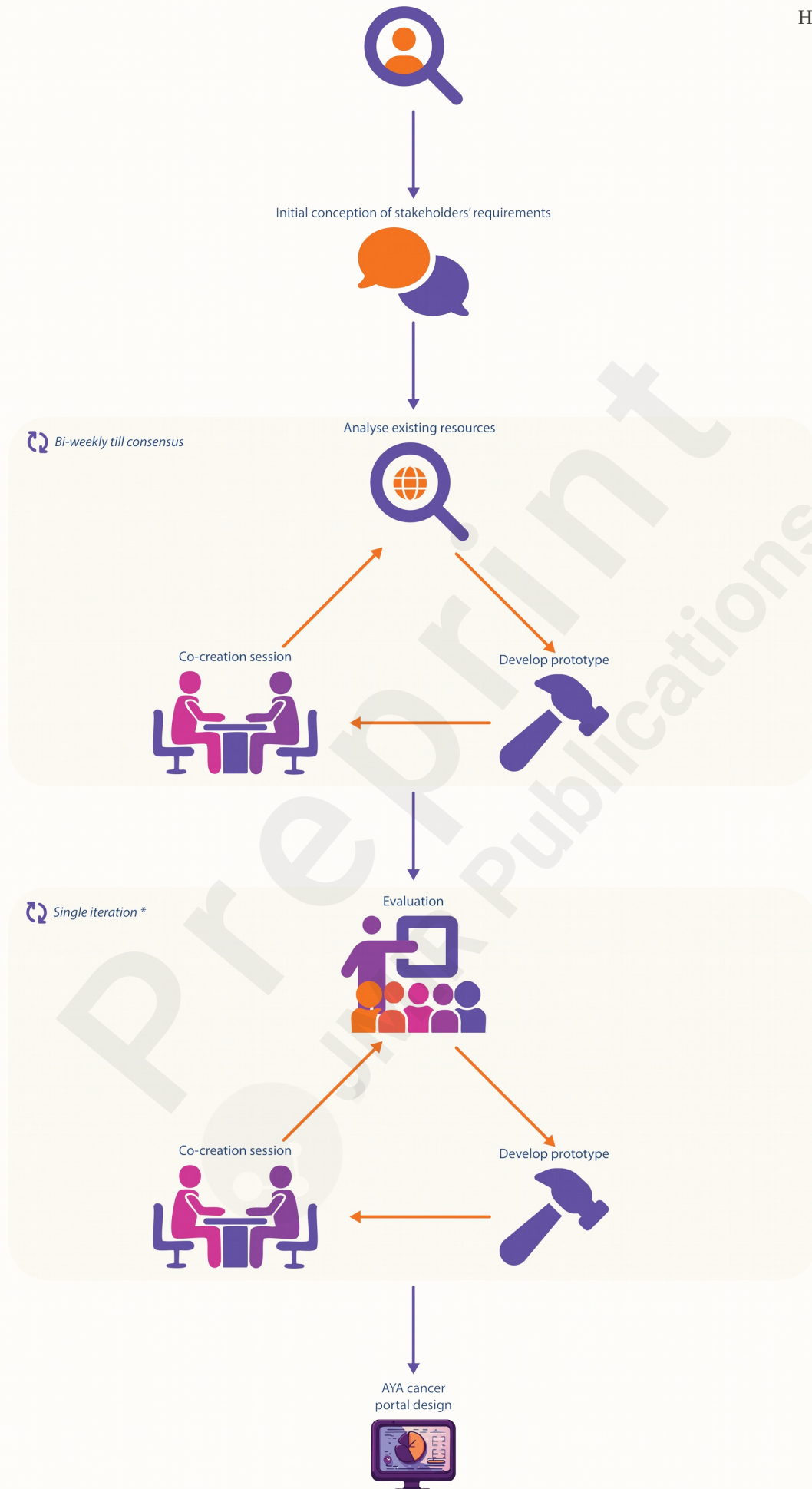


Figure 1: Schematic overview of the design process for the AYA information cancer portal. * In the single iteration we consulted 5 patients advocates prior to further developing the prototype, after further prototype refinement, we consulted 3 of the 5 initially consulted patient advocates to evaluate if their remarks were addressed appropriately. Embedded icons and figures were obtained through Font Awesome and Adobe Firefly.

Proof-of-concept

Technical feasibility was evaluated through a minimally functional proof-of-concept (PoC); minimally functional being where the general look and feel, use case exploration, and core functionality were implemented, but features such as filtering, usage guidance, and multiple visualisation options were not available. The testing focused on an aggregate data extraction from a Vantage6 federated infrastructure via an independent intermediary – or service provider – providing the analyses to people who cannot access the federated infrastructure directly. This work was previously presented at Medical Informatics Europe 2025, and details can be found in the associated conference proceedings²⁵. The code we used is publicly available on GitHub²⁶.

Results

Setting of the portal

To limit the number of people accessing the FL infrastructure – which would provide a form of access to sensitive data, we decided not to situate the AYA cancer portal directly within STRONG-AYA but instead create a curated repository of CfC-approved use cases²⁷. This repository serves as an intermediary between the portal and the FL infrastructure, whilst human curation ensures that it contains analyses aligned with the approved use cases. The use case data will be periodically updated through scheduled federated queries that are independent of portal use, to reduce unnecessary system load and portal latency. Herein, the federated queries are handled by a typical Vantage6 federated infrastructure¹⁰ with a centralised aggregator. A schematic overview of the AYA cancer portal's setting and technical setup can be found in Error: Reference source not found.

Portal requirements

All interviewed stakeholders showed great interest in overcoming the general lack of publicly available information across AYA cancer. Specific interests in using the portal varied by stakeholder group. AYAs who have received a diagnosis – but have not yet began treatment – prioritised information to empower them in decisions with their HCPs and medical teams, whereas AYAs who have already completed treatment seek the possibility to compare their outcomes to other AYAs and hope to have a simplified dossier of their cancer related medical history and a better idea of how their experience relates to that of others. In line with this, one of the aspects that was mentioned during the interviews was:

“Some of the AYAs like to know if they need support. If you’re for example tracking your anxiety levels, having this digital resource showcase some of the support networks or places to find reliable information is something quite important.”

AYA perspective

Regardless of where along the cancer continuum they were, AYAs identified a need to independently

navigate the portal, as certain topics – such as sexuality – were best explored individually, to reduce risks of distrust or taboo. This was resonated by the following quote:

“Given the distance the portal gives from the clinic and the opportunity to look at information in your own space, this portal could reduce patient discomfort.”

AYA perspective

In contrast, representatives of policymakers mentioned aspects as:

”A lot is about best practice sharing and about setting targets across regions. Imagine I’m part of an advocacy group that would like to push for all EU member states to take actions to increase their survival rate to at least X by date Y.”

Policymaker perspective

Clearly indicating that policymakers seek policy-actionability information on geographical, cultural or social disparities and wish to reduce the societal burden of AYA cancer. HCPs also seek such information, to gain insight in cancer system needs, such as staffing requirements, and create a narrative/business-case for specialist AYA cancer care in their setting. Lastly, most HCPs want to provide tailored information to their AYA patients:

“In consultation you want to show a young person how many people have this illness here and in other places. What do various aspects of life look like? What does mobility look like a year later? What do the chances of having a baby look like?”

HCP perspective

This may refer to that HCPs wish to help the AYA navigate their cancer landscape, whilst explaining the situation that the AYA finds themselves in, using information they – the AYA – can also access themselves.

A scientific interest was described as:

“Who is at risk of poor physical and psychosocial outcomes, and what mechanisms are behind this risk?”

Scientific researcher perspective

From that, we deduced that scientific researchers seek a distinct degree of modifiability and the freedom to explore research questions, beyond pre-defined use cases. Therewith we considered scientific researchers to be best catered for by the native interface of the Vantage6 federated infrastructure software, to provide this flexibility. Scientific researchers were thus not taken into further account in the development process of the portal prototype.

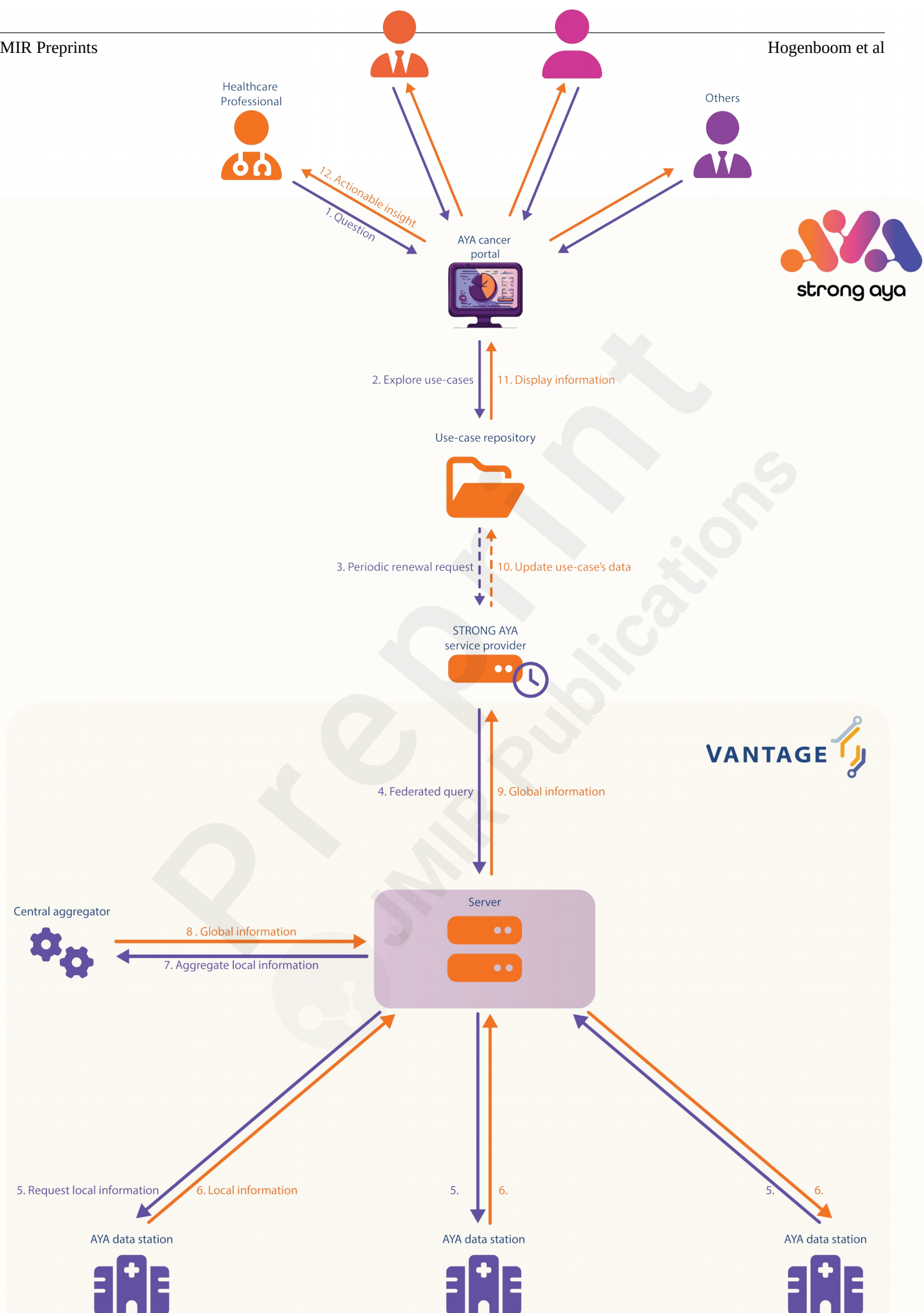


Figure 2: Schematic overview of the AYA cancer portal's setting in STRONG-AYA. Embedded icons and figures were obtained through Font Awesome and Adobe Firefly.

In line with these preferences, we considered the typical diversity and characteristics of stakeholders and developed a set of specific design requirements, which are detailed in Table 2. Despite diverse stakeholder characteristics, with various levels of educational attainment, health literacy, and wide interests, all sought a high degree of accessibility, understandability, and relative simplicity in use. Herein, accessibility means that it should be easily accessible without technical knowledge, understandability refers to visualisations and descriptions that need little explanation, whilst simplicity calls for pre-defined sets of information without having to compose everything on the spot.

Despite these three clearly identifiable requirements, our stakeholders had diverse backgrounds, with various levels of educational attainment, health literacy, and wide interests. We identified specific requirements for stakeholder groups based on either desires or typical characteristics that – generally – complement our three core requirements outlined above. AYAs' pre- or on-treatment would value decision aids which they can both access autonomously, but also together with an HCP, particularly for AYAs who tend to display avoidant behaviour. Post-treatment, AYAs' focus shifts towards a portal giving an insight into their outcomes and well-being over the long-term. Therefore, the portal should adapt based upon illness phases. Policy related questions – regardless of who is asking them – need quick numerical summaries and high-level information that can be used to support a case for a new policy or regulation; in contrast HCPs seek a degree of individual modifiability and a higher level of detail that allows them to 'paint' a more individual-AYA relevant 'picture' during a clinical consultation.

The personas that were developed from the interviews that underpin these desires and requirements can be found in [Error: Reference source not found](#) and [Error: Reference source not found](#).

Table 2: AYA cancer portal requirements with organisational requirements in italic.

Requestee	DESIRES	Requirement
STRONG-AYA COMMITTEE FOR COORDINATION	<i>Governance and Privacy</i>	<i>Access control</i> <i>Use-case-driven</i>
AYAs and confidantes Pre- or on-treatment	Variable degree of engagement Correct info at the correct time Independence	Accessible Decision aid together with HCP Autonomous access Easy to understand
AYAs and confidantes Post-treatment	Monitor well-being Sporadic interaction Community creating and comparison with peers Correct information	Simple and relaxed Flexibility in engagement Own data exploration
Healthcare professionals Medical perspective	Help AYAs navigate the landscape Explain what is happening to them	Accessible Understandable Modifiability
Healthcare professionals Policy perspective	Care needs Specialism necessities Staffing requirements Business-case/narrative creating	Accessible Simple Narrative creating
Polymakers	Regional disparities Societal impact Policy-actionable info	Quick numerical and statistical summaries High-level information

Alternative designs

From the existing designs we identified, we extracted certain design ideas and patterns that reflect the requirements described in table 2, most notably; modularity of information, flashcard-inspired aesthetics accompanying descriptive text, simple filtering options, and the optimal amount of interactions required on any one page.

With modularity of information (as e.g. in the Global Cancer Observatory portal²¹) we sought to incorporate simplicity and fulfil the organisational requirement of a use case organised portal. Using a flashcard aesthetic accompanied by text (inspired by ‘Decision Helper’ by Stine R. Søndergaard¹³) we aimed to achieve understandability and provide rapid numbers but embedded context to aid users’

understanding and interpretation. We chose filtering inspired by web-shops, to achieve accessibility and modifiability, while remaining understandable and easy to use. To collect this in a portal that is in line with the various requirements, we then gathered these components in a layout striving to seek a balance between distinct usability and visual cues, and clarity and calmness aiming to make the portal accessible to people of all walks of life.

Preliminary prototype

The various elements outlined above were incorporated in a preliminary prototype of three ‘main’ pages, namely: a landing page with profile selection, a module selection page allowing users to select a certain subject (or use case) and a module page dedicated to the selected subject. The three preliminary pages are visible in Error: Reference source not found to Error: Reference source not found. Herein, the design elements of the alternative designs were included in the prototype and underwent setting-specific adaptations in concordance with the discussions of the co-creation sessions. In this prototype, accessing the information requires three interactions: selecting a profile, selecting a module, and navigating the selected module.

Next to the distinct design elements outlined above, we put into practice our ambition of a balanced layout, with an aesthetic based upon soft colours, ample whitespace, and simple figures. Here we also strived to incorporate accessibility requirements – using colour-blind friendly colours and sufficient whitespace for users with other visual impairments. We remained influenced by the early phases of our co-creation, deciding that information-sparse displays are more suitable for our setting and stakeholders. Whereas information-dense displays were deemed too complex, research-oriented, and too ‘dashboardy’. An example of the early information-sparse and information-dense displays can be found in Error: Reference source not foundError: Reference source not found.

Prototype evaluation

During the evaluation of our preliminary prototype, patient advocates and workshop attendees’ were generally very enthusiastic and positive. Some participants identified further improvements: greater

attention to possible anxiety induced by seeing – or the potential to see – upsetting information; a context-aware glossary explaining terminology on the portal; an information search function; improved visual cues to scroll the screen; and balance of graphics and text. An overview of strengths and shortcomings that we extracted from our evaluation sessions is available in Table 3.

Various further suggestions related to guidance upon using the portal well, community and professional support, the necessity of considering differences in cultural and ethnical backgrounds, and differences in maturity and – health – literacy levels.

Table 3: Key qualities of the evaluation of the preliminary prototype and remarks raised during evaluation sessions.

Evaluators	Quality	Key points
PATIENT ADVOCATES INVOLVED IN CO-CREATION (5 AYAS WITH LIVED EXPERIENCE)	Strengths	Clean and slick look Soft colours Simple and understandable Very necessary tool High uptake by existent AYA community
	Shortcomings	Limited consideration for anxiety Limited glossary and explanation Findability of info can be improved <i>“Will there be guidance in using the portal? Both in text as in short videos?”</i>
	Questions and remarks	<i>“Will there be a community attached to the portal?”</i> <i>“Will the portal contain appropriate references to professional support for those who seek it?”</i>
STRONG-AYA Open Portal Workshop (10 HCPs, 1 AYA with lived experience, and 1 scientific researcher)	Strengths	Clean looking Understandable User-friendly Easy to navigate
	Shortcomings	Can be perceived as overly graphic Insufficient horizontal scrolling cues Restriction of always having to use visuals
	Questions and remarks	<i>“What languages will the portal be available in?”</i>

“How will you take differences in maturity and literacy levels into account?”

“It will be necessary to continuously evaluate the portal to include portal perspectives of different social and ethnical backgrounds.”

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Final prototype

The shortcomings, questions, and remarks that were identified in the evaluation of our preliminary prototype were then incorporated in a final prototype as a last iteration of our co-creation process. This final prototype is displayed in Error: Reference source not found-5 and is more extensively demonstrated in a video available on our GitHub²⁶.

We focussed on each design-specific shortcoming: possible anxiety; more guidance on use; glossary; information search function; and horizontal scrolling indicators, which were incorporated as extra elements while maintaining the prototype's perceived strengths. Next to this we included a 'numbers-only' view in the module page as an alternative to extensive graphics (mostly preferred by HCPs and policymakers – an example hereof is shown in Error: Reference source not found). Some shortcomings, questions, and remarks were not amended, as they were considered content-specific rather than design-related.

Proof-of-concept

We demonstrated PoC, to deploy a publicly facing portal whilst leveraging our Vantage6 based federated infrastructure in a curated yet open way. This concept is publicly available at our GitHub Pages²⁸. Apart from demonstrating that we were able to deploy a public portal in our setting, it also showcases how a portal can be openly accessible for anyone, aligning with the requirement of autonomous access.



Figure 3: Final prototype of the preliminary profile page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.



Figure 4: Final prototype of the preliminary module selection page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.

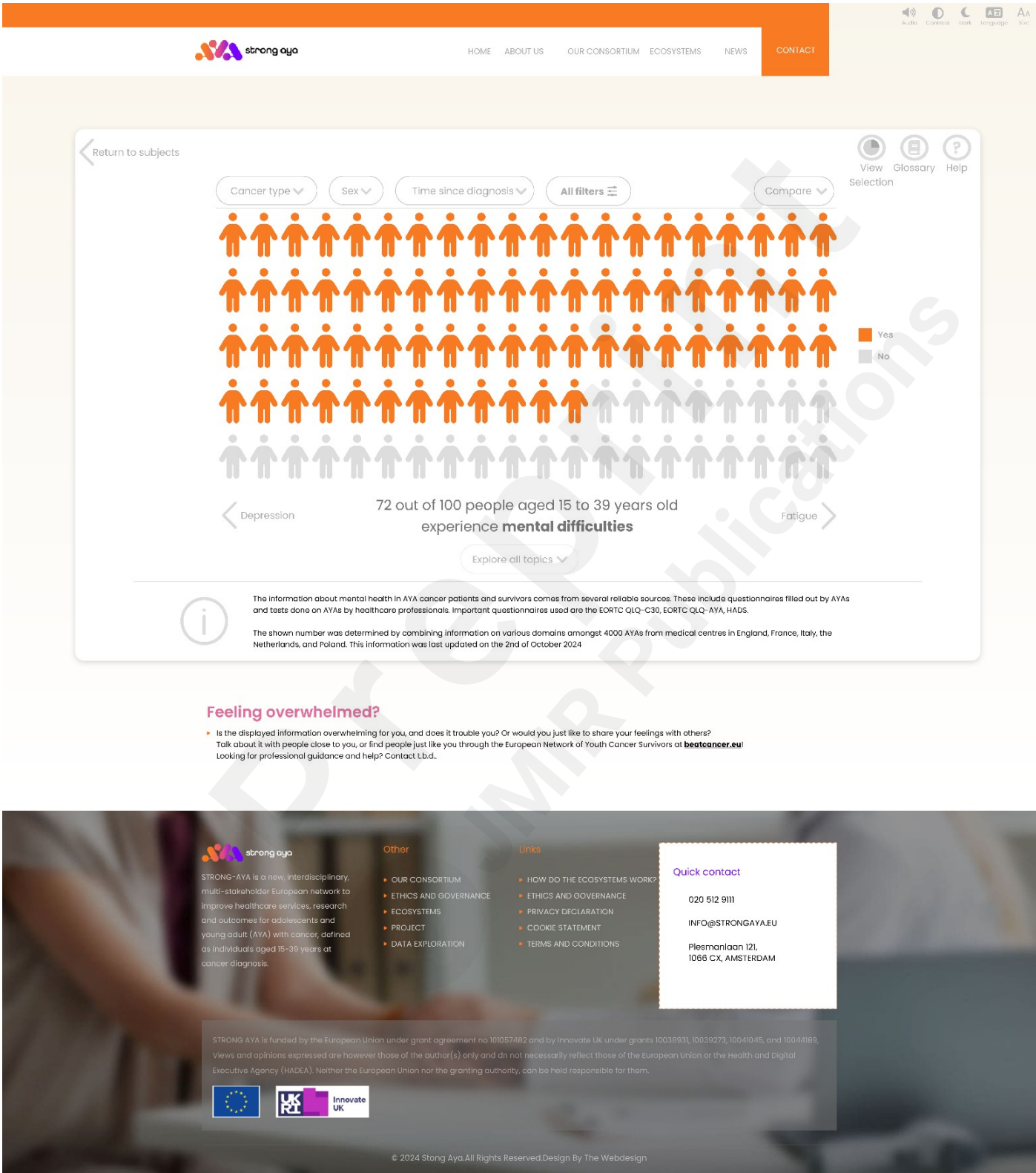


Figure 5: Final prototype of the preliminary module page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.

Discussion

In this study, we aimed to leverage the unique opportunities presented by the STRONG-AYA ecosystem to address the need for widely accessible evidence-based AYA cancer information. To achieve this, we first identified the information needs of various stakeholders. Building on this understanding, we then developed a detailed design for an AYA cancer-tailored FL-based information portal through an iterative co-creation process involving AYAs with lived experience and researchers. Stakeholders in the AYA cancer landscape need evidence-based information that captures their interests, desires, and needs. People in the AYA cancer landscape generally seek information that can empower their decisions; from decisions relating to personal well-being and treatment regime to organisation of care, from patient guidance to psycho-social challenges and policymaking. These stakeholders not only have heterogeneous interests, but they also come from diverse backgrounds and have varying educational as well as digital and health literacy levels. Informed by this, we developed a prototype for a public AYA cancer information portal that leverages the STRONG-AYA ecosystem. We developed this prototype through various iterations in an AYA with lived experience and scientist co-creation process. The prototype underwent external review by means of an AYA think-aloud session and a workshop with AYAs and HCPs – both being good practice in patient engagement and involvement²⁹. The prototype was generally well-received and appreciated for its relevance, balanced design, clear information, and perceived user-friendliness. Positive reception was attributed to our use of soft colours, the limited amount of information displayed per page, and the accompanying descriptions, which have all already been identified as important components in enhancing interpretability for example patient reported outcome measure data³⁰. Significant design shortcomings observed during this review consisted of the absence of guidance on how to use the portal, and the findability of information spread across and inside the modules. Moreover, the design gave only limited consideration to potentially upsetting information for the AYA audience – both in terms of what information is presented, and particularly how it is communicated. Ambiguous or

poorly presented information might exacerbate existing health anxiety and induce cyberchondria – hypochondria induced by excessive online information uptake, countering the otherwise positive value return the portal could have in regards of improving the patients' experience³¹. In a last iteration of our co-creation process, we included such design elements aiming to provide a solid basis for an AYA cancer information portal that is accessible and usable to people of all walks of life. Lastly, we demonstrated that we could leverage a Vantage6 infrastructure for such an AYA cancer portal in an open, yet curated and secure manner²⁵.

As part of our design cycle, we considered various existing resources with similar purposes. In this, we selected design elements and usability cues we considered to be most suitable and adapted them through co-creation. When comparing our prototype to existing resources we observe that we aimed to cater to various stakeholders through the ability to change views (i.e. change visuals), whereas existing resources often are catered for a specific audience. This approach has led to functionalities that allow users to deviate from recommendations found in literature. For instance, the icon array is a common visualisation method for patient population statistics^{13,32}. Our proposed design allows users to deviate, for instance by select the 'numbers-only' view. However, recommending a visualisation style tailored to each stakeholder group, rather than imposing a fixed one, may be more pragmatic. This approach allows individual users within a stakeholder group to choose their preferred visualisation style per data type, as not everyone has the same preferences³⁰. Regardless, we encourage researchers in finding optimal ways to display AYA-content, both to AYAs as to other stakeholders in the AYA landscape.

When comparing our setup with that of similar resources, what truly sets the STRONG-AYA cancer information portal apart is the use of a FL-ecosystem as backbone. This allows the STRONG-AYA cancer information portal to practically be up to date with the latest insights. Another unique element of the STRONG-AYA cancer information portal is that our proposed setup allows people to autonomously access this FL resource using pre-defining use case without sacrificing privacy.

Strengths and limitations

With our co-creation approach and review processes we aimed to incorporate perspectives of a diverse audience, yet we acknowledge that our method has its limitations and is far from exhaustive in this respect. One strength of our study is that the patient advocates who participated in our co-creation process are experienced in AYA research and advocacy, enabling them to effectively represent various voices from the patient perspective. However, it is important to acknowledge that these advocates, while experienced, have high literacy levels and may still not fully capture the diversity of experiences and backgrounds among all AYAs. Therefore, continuous testing and use of the portal should actively seek to include and promote uptake among underserved and underrepresented populations to ensure broader applicability. Furthermore, whilst the participating patient advocates come from various countries (Germany/USA, Portugal, Slovenia, and Sweden), it is challenging to account for the full range of cultural differences related to personal well-being and medical treatment. This was also echoed by HCPs during our *Open Portal Workshop*, who highlighted that certain information might be sensitive or taboo for minority groups that were not included in the prototype development phase.

To address this, future work must in part prioritise co-creation with underrepresented groups – not only to adapt content presentation but first to determine whether and how they wish to engage with the portal, ensuring resources are allocated to features they will actually use. One such mechanism might take the form of built-in tools allowing users to express the perceived usability and appropriateness throughout the portal's lifetime. Similarly, stakeholders such as policymakers and private companies, though identified as relevant to the AYA cancer landscape, were not explored in depth in this study. Our initial conception of their requirements was preliminary, and further engagement with these groups is necessary to ensure the portal aligns with broader priorities and interests. Broadly speaking, we now focussed on qualitative feedback of AYAs and HCPs, whereas an alpha and beta version of the portal should incorporate structured usability testing, quantitative

metrics, and include validated evaluation tools, as we here focussed on detailed qualitative feedback for the initial co-creation of this platform. This will enable more detailed insights into the portal's design, thereby ensuring that it meets the needs of all its users while remaining current and timely.

Furthermore, whilst the current prototype incorporates suggestions for accessibility features, these were not fully developed. Incorporating features that assist those with cognitive or visual impairments is essential for ensuring the portal's inclusivity and usability across diverse user groups and is obligatory in many jurisdictions.

Future directions

In future, we will seek to engage additional stakeholders more fully than in this study, such as national and private bodies. Alongside this, we will develop a function for AYAs to explore their own data, where there is sufficient administrative and infrastructural support to facilitate this. Irrespective of that, to deploy the outlined AYA cancer information portal, defining relevant use cases, assessing which are suitable for a specific stakeholder, and controlling access thereto is a necessary exercise in the portal's realization.

Furthermore, the use case-driven design of our portal ensures a high degree of flexibility and modularity, enabling us to incorporate new use cases and adapt to evolving stakeholder needs. This adaptability is crucial for the portal's long-term success and can also foster data solidarity throughout the portal's lifetime. Inclusion of structured and validation evaluation tools and appropriate accessibility options are equally important in its realisation.

To ensure the long-term sustainability and applicability of the portal, we recognise the need for a robust financial model and collaborative partnerships. An initial business modelling of the project conducted an analysis of possible revenue streams for the project and considered which were the most appropriate in the short-, middle-, and long-term. Funding of the portal (for activities such as further development, and alpha and beta testing and roll-out) might best be sourced from further research grants and service fees for access to the federated ecosystem for parties outside of the

STRONG-AYA consortium – within the bounds of our defined terms and conditions. Strategic partnerships that enable the embedding of the portal within (inter)national networks for AYA cancer care and eventually its integration in routine care and research, are possible long-term revenue sources and provide associated operational budgets. Such collaborations would not only provide financial support but also enhance data acquisition and expand the portal's reach and impact.

Ownership of the portal should ideally be shared among key stakeholders, including national and international bodies, AYA advocates, HCP representatives, and perhaps even private parties. This collaborative approach ensures that the portal remains relevant, inclusive, and sustainable. Overall governance and responsibility for operations of the portal, at present, may stay within the STRONG-AYA consortium but ownership of it should remain flexible given that new parties may join future iterations of the project, or imbed the portal within other countries and settings. Lastly, once fully developed, the success of the portal will be determined by well-considered promotion amongst stakeholders, and specifically amongst newly diagnosed AYAs as they ought to be informed about the portal.

Conclusion

Overall, an AYA cancer information portal leverage the STRONG-AYA ecosystem is necessary and desired by all the relevant stakeholders. For such a portal we found that stakeholders' desires and requirements vary and called for specific adaptations of existing designs. By means of co-creation, we designed a prototype portal that was generally perceived as something very usable and sought after. Importantly, we were also able to demonstrate that we can leverage the unique ecosystem that STRONG-AYA is setting up without sacrificing data security and privacy. The potential value return to the AYAs contributing to the ecosystem is significant, as they can actively see their data is used to contribute to AYA cancer care and generate evidence-based insights.

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All individuals that have contributed to this study are included in the author list except for those that were interviewed for the requirement gathering phase, the larger group of AYAs with lived experience part of our co-creation process and workshop attendees. The authors would however like to express their gratitude to those who contributed to the requirement gathering phase and would like to express a special gratitude to the AYAs with lived experience involved for their role in the evaluation of the portal prototype. We also express our gratitude to the Dutch National Research and Education Network: SURF, for use of the SURF Research Cloud infrastructure in our proof-of-concept. We used generative artificial intelligence for the following tasks: Mistral AI's Le Chat Pro for typographical checking and Adobe Firefly for image generation.

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Conflicts of Interest:

None declared.

Data Availability:

No data to share. The code used for our proof-of-concept is available under apache-2.0 licence on GitHub: <https://github.com/STRONGAYA/strong-aya-info-portal>

Abbreviations:

AYA:	Adolescent	and	Young	Adult
CfC:	committee	for		coordination
FL:		Federated		Learning
HCP:	Healthcare Professionals			

Prior presentation:

This study and its results are original and have not been presented elsewhere and will only appear as preprint on Journal of Medical Internet Research (JMIR) Preprints.

References

1. Collaborators GBDAYAC. The global burden of adolescent and young adult cancer in 2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Oncol.* Jan 2022;23(1):27-52. doi:10.1016/S1470-2045(21)00581-7
2. Hughes T, Harper A, Gupta S, et al. The current and future global burden of cancer among adolescents and young adults: a population-based study. *Lancet Oncol.* Dec 2024;25(12):1614-1624. doi:10.1016/S1470-2045(24)00523-0
3. Vlooswijk C, Janssen SHM, Sleeman SHE, et al. Identifying the informational needs and sources of support of Adolescent and Young Adult (AYA) cancer survivors to inform the development of a digital platform. *J Cancer Surviv.* Oct 18 2024;doi:10.1007/s11764-024-01679-z
4. Baudry V, Girodet M, Lochmann M, et al. Supportive care needs of adolescents and young adults 5 years after cancer: a qualitative study. *Front Psychol.* 2024;15:1268113. doi:10.3389/fpsyg.2024.1268113
5. Ung Kræft – fællesskab for unge kræftpatienter og pårørende. <https://cancer.dk/ungkraeft>
6. Jong & kanker. <https://www.kanker.nl/jong>
7. Sustersic M, Gauchet A, Foote A, Bosson JL. How best to use and evaluate Patient Information Leaflets given during a consultation: a systematic review of literature reviews. *Health Expect.* Aug 2017;20(4):531-542. doi:10.1111/hex.12487
8. Carini E, Villani L, Pezzullo AM, Gentili A, Barbara A, Ricciardi W, Boccia S. The Impact of Digital Patient Portals on Health Outcomes, System Efficiency, and Patient Attitudes: Updated Systematic Literature Review. *J Med Internet Res.* Sep 8 2021;23(9):e26189. doi:10.2196/26189
9. Dyke SO, Dove ES, Knoppers BM. Sharing health-related data: a privacy test? *NPJ Genom Med.* Aug 17 2016;1(1):160241-160246. doi:10.1038/npjgenmed.2016.24
10. Moncada-Torres A, Martin F, Sieswerda M, Van Soest J, Geleijnse G. VANTAGE6: an open source priVAcY preserviNg federaTed leArninG infrastruCTurE for Secure Insight eXchange. *AMIA Annu Symp Proc.* 2020;2020:870-877.
11. The Personal Health Train Network. <https://pht.health-ri.nl/>
12. The STRONG-AYA Initiative. <https://strongaya.eu>
13. Søndergaard SR, Stie M, Bechmann T, et al. Through Clinicians Eyes: Use of an In-consultation Patient Decision Aid in Radiation Treatment for Early Breast Cancer. A Qualitative Study. *Clin Breast Cancer.* Jun 2024;24(4):e297-e309. doi:10.1016/j.clbc.2024.02.009
14. Cancer Research UK. <https://www.cancerresearchuk.org/>
15. Gottardelli B, Gouthamchand V, Masciocchi C, et al. A distributed feature selection pipeline for survival analysis using radiomics in non-small cell lung cancer patients. *Sci Rep.* Apr 3 2024;14(1):7814. doi:10.1038/s41598-024-58241-1
16. Tomko C, Davis KM, Luta G, Krist AH, Woolf SH, Taylor KL. A comparison of web-based versus print-based decision AIDS for prostate cancer screening: participants' evaluation and utilization. *J Gen Intern Med.* Jan 2015;30(1):33-42. doi:10.1007/s11606-014-2994-7
17. Smits D, Van Beusekom B, Martin F, Veen L, Geleijnse G, Moncada-Torres A. An Improved Infrastructure for Privacy-Preserving Analysis of Patient Data. *Stud Health Technol Inform.* Jun 29 2022;295:144-147. doi:10.3233/SHTI220682
18. Martin F, Beusekom B, Leurs R, et al. vantage6. 2025.
19. Linder O. Operational plans for the pan-European umbrella ecosystem. 2024(Deliverable D4.7). doi:10.5281/zenodo.17232800
https://strongaya.eu/wp-content/uploads/2025/07/D4.7_Operational_plan_pan_European_ecosyst

em_STRONGAYA_v2.0_30092024.pdf

20. Den Dekker T. *Design thinking*. Routledge; 2020.
21. Ferlay J, Ervik M, Lam F, et al. Global cancer observatory: cancer today. Lyon, France: international agency for research on cancer. 2018.
22. Santeon. Santeon ontwikkelt patiëntgerichte infographic. Accessed May, 2025. <https://santeon.nl/2021/12/09/samenbeslissenborstkanker-patientgerichte-infographic/>
23. Couespel N, Venegoni E, Lawler M. The European Cancer Pulse: tracking inequalities in cancer control for citizen benefit. *Lancet Oncol*. May 2023;24(5):441-442. doi:10.1016/S1470-2045(23)00140-7
24. Shipman LA, Price J, Abdulwahid D, et al. Service Evaluation of MyChristie-MyHealth, an Electronic Patient-Reported Outcome Measure Integrated Into Clinical Cancer Care. *JCO Clin Cancer Inform*. Apr 2024;8:e2300162. doi:10.1200/CCI.23.00162
25. Hogenboom J, Lobo Gomes A, Dekker A, Van Der Graaf W, Husson O, Wee L. From Federated Learning to Publicly Facing Platform; Proof-of-Concept of the STRONG AYA Information Portal. IOS Press; 2025:
26. Hogenboom J. STRONG AYA Information Portal. 2025. doi:10.5281/zenodo.17366913 <https://github.com/STRONGAYA/strong-aya-info-portal>
27. Stark DP. Repository of use cases of the ecosystems. 2023(Deliverable D4.8). doi:10.5281/zenodo.17233175 https://strongaya.eu/wp-content/uploads/2025/07/D4.8_REPOSITORYUSECASES_STRONGAYA_v1.pdf
28. Hogenboom J. STRONG AYA Information Portal Pages. October, 2025. <https://strongaya.github.io/strong-aya-info-portal>
29. Oveisi N, Cheng V, Taylor D, et al. Meaningful Patient Engagement in Adolescent and Young Adult (AYA) Cancer Research: A Framework for Qualitative Studies. *Curr Oncol*. Mar 22 2024;31(4):1689-1700. doi:10.3390/curroncol31040128
30. Albers EAC, Fraterman I, Walraven I, et al. Visualization formats of patient-reported outcome measures in clinical practice: a systematic review about preferences and interpretation accuracy. *J Patient Rep Outcomes*. Mar 3 2022;6(1):18. doi:10.1186/s41687-022-00424-3
31. McMullan RD, Berle D, Arnaez S, Starcevic V. The relationships between health anxiety, online health information seeking, and cyberchondria: Systematic review and meta-analysis. *J Affect Disord*. Feb 15 2019;245:270-278. doi:10.1016/j.jad.2018.11.037
32. Hasannejadasl H, Roumen C, Smit Y, Dekker A, Fijten R. Health Literacy and eHealth: Challenges and Strategies. *JCO Clin Cancer Inform*. Sep 2022;6:e2200005. doi:10.1200/CCI.22.00005

Supplementary material

Supplementary Table 1: Guiding questions for the adolescent and young adult with lived experience of cancer-think aloud session. Questions were inspired by the evaluation of the MyChristie-MyHealth app (DOI: 10.1200/CCI.23.00162).

“How appealing does the STRONG-AYA Portal look?”

“How understandable are the visuals and the accompanying explanations?”

“Would you need or like a lot of guidance in using the STRONG-AYA Portal?”

“How would you use it yourself?”

“Do you think you will be able to find the information that you would like to know?”

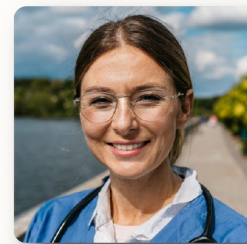
“How do we ensure that (especially newly diagnosed) people get directed to the platform?”

“Are you missing any elements?”

“Would you want to use the STRONG-AYA Portal?”

Pauline, 53 years old, senior oncologist

Pauline is a resident in a medium-sized hospital in Normandy, France. In Pauline's department, they have the ambition to setup an AYA cancer care service and Pauline is the driving force behind this development. Pauline now faces the necessity of needing a business case that can stress the service's relevance and its practical requirements to the board of directors and other funding institutions.



As part of this case, Pauline would for instance like to know:

"How many AYAs would like to see a specialised nurse, and thus, how many full-time equivalents (FTE) do we need per referral?"

"How many AYAs that we see are likely to require chemotherapy?"

"How many of the AYAs that we will receive with this new service require hospitalisation, and thus, would we require extra capacity for these new referrals?"

Pauline has limited time to work on this case, and for instance would require:

"Accessibility, without requiring in-depth technical knowledge."

"Clarity, with figures and numbers on information of suggested topics."

"Modifiability, allowing Pauline to create a realistic narrative for this medium-sized hospital."



Baerke, 19 years old, photography student

Baer is a photography student and handball player from Limburg, the Netherlands and was recently diagnosed with colon cancer. Baer is in disbelief. He is refusing to come to terms with his condition and can't even start to think about what is going to happen to him, and what the future holds for him. Yet, caregivers hope to be able to help him in making the right decisions for him.

As part of this case, Baer would for instance like to know:

"Will I now forever remain, Baer the cancer patient?"

"What is the likelihood that I will be able to live a 'normal' life?"

"Will I be too tired to keep playing handball?"

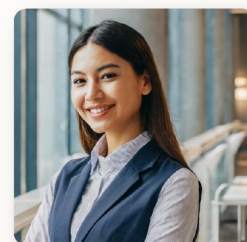
To allow Baer to make the right decisions, it would for instance require:

"Concise info shown by healthcare practitioner."

"Little interaction but the right information."

Allison, 39 years old, researcher

Allison works as a researcher in Muntenia, Romania. Allison has the ambition to generate valuable contributions to the scientific knowledge on AYA cancer care. For that, Allison hopes that she can identify meaningful scientific hypotheses, and ideally, test those hypotheses.



As part of this research, Allison would for instance like to know:

"What differences between treatment outcomes can be identified, and are there specific patterns that appear to play a role?"

"What is the quality of this data, what are existing biases, and what does the data actually represent?"

"How many of the AYAs that we will receive with this new service require hospitalisation, and thus, would we require extra capacity for these new referrals?"

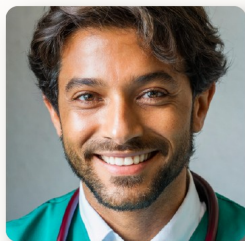
To allow Allison to contribute to AYA cancer care knowledge, it would for instance require:

"Flexibility, allowing Allison to build analyses that feed into her hypotheses."

"Modifiability, allowing Allison to identify meaningful hypotheses."

"Quality assurance, allowing Allison to form reliable insights."

Supplementary Figure 1: Personas representing a policy making healthcare professional, an adolescent and young adult cancer patient, and a researcher. Names, and images were computer generated and represent fictional characters. The views that these characters portray represent accumulated opinions and thoughts obtained through various interviews. Images of these fictional characters were generated using Adobe Firefly.



Lazzaro, 38 years old, specialised nurse

Lazzaro works in a tertiary hospital in Campania, Italy. Lazzaro's hospital has dedicated AYA cancer care services and he is one of the specialised nurses often having conversations with AYAs. When speaking to an AYA, Lazzaro would like to be able to draw a picture of how various aspects in the AYAs life are likely to look.

To help the AYA face their illness, Lazzaro would for instance like to know:

"How can we guide AYAs with a decision on postponing their treatment for the sake of conserving fertility, at cost of cancer progression, and how does this affect their life?"
"What do the chances for survival look like?"

Lazzaro is likely to look at this information together with an AYA, and this for instance would require:

"Accessibility, without requiring in-depth technical knowledge."
"Clarity, with figures and numbers on information of suggested topics."
"Explainability, providing information that is easy to explain to any AYA."
"Modifiability, allowing Lazzaro to draw a more relevant picture."

Ada, 64 years old, policy maker

Ada is from Lower Silesian in Poland and is a policy maker in Europe.

Ada seeks to improve healthcare across regions and hopes to minimise negative societal and economical effects. For that, Ada seeks insights that help in setting up initiatives where they are actually necessary.

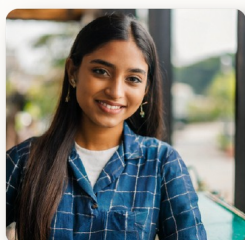


To uncover what pain points have to be acted on, Ada would for instance like to know:

"What are regional disparities in AYAs number of life years lost, and who do we incentive to share their best practices with other regions?"
"What is the societal impact of late-effects in a demographic that carries a burden for so long, and what initiatives can we set up to mitigate those?"

Ada is not necessarily part of any AYA community, and would for instance require:

"Policy-actionable insights, providing very concrete and direct figures and numbers."
"Simplicity, straightforward information on a very high level."



Rhys, 28 year old, bartender

Rhys is a bartender from South Glamorgan, Wales.

Just over three years ago, Rhys was diagnosed with a brain tumour and her illness is currently perceived as stable.

Rhys is however very much aware that she will never truly be disease-free. Consequently, Rhys realises that her situation might not always remain stable, and would like to monitor her wellbeing so that she can act on changes in her wellbeing.

To life beyond her illness, Rhys would for instance question:

"How often do people like me fear that their cancer will progress drastically, and does this fear influence their social abilities?"
"I feel more and more tired recently, is this normal? Might there be something else that is influencing my energy levels?"

Rhys would like to independently look at such information, and this would for instance require:

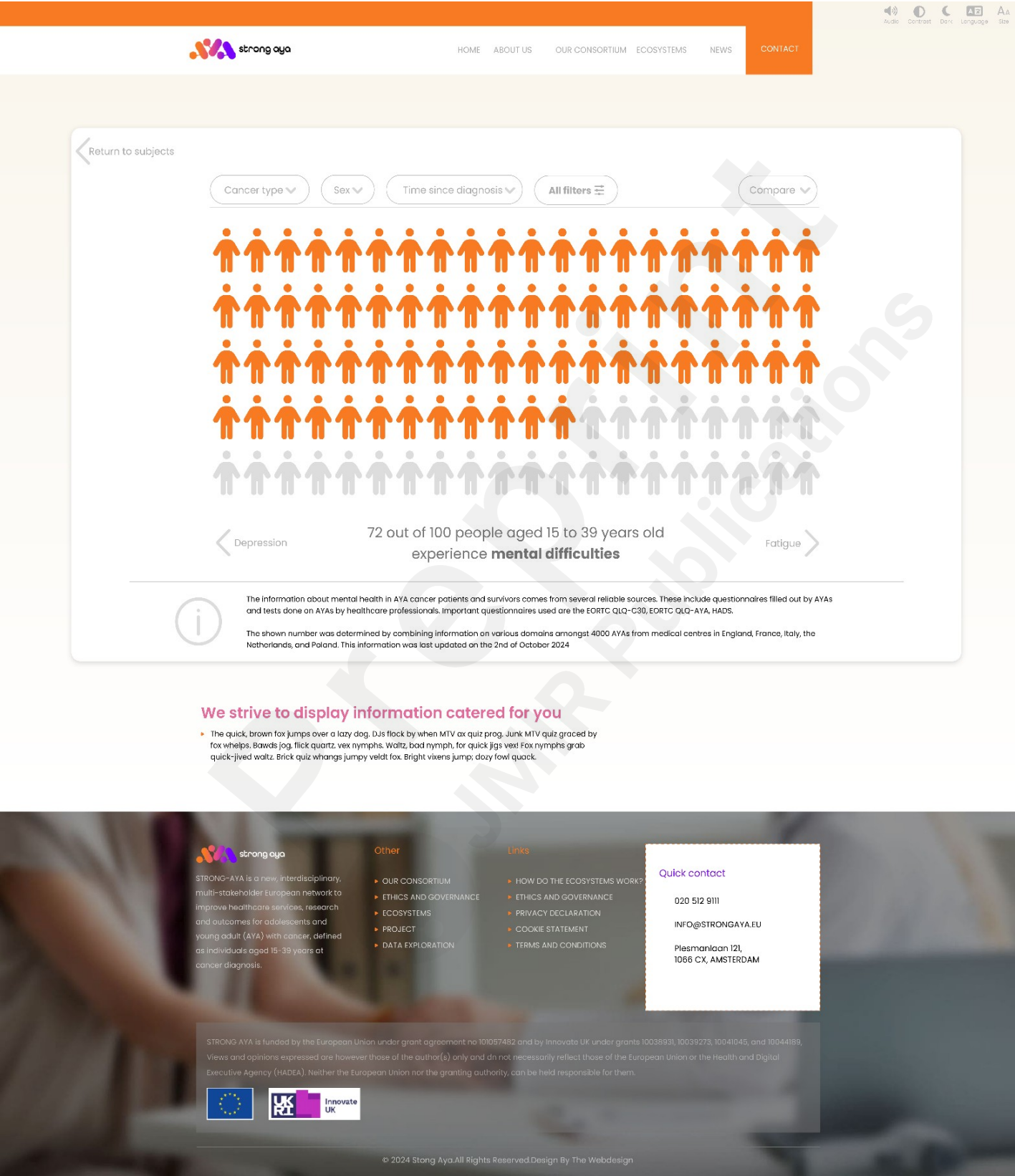
"Simple information in easy and relaxed format."
"Non-committal reminders and monitoring."
"Insight into own history."



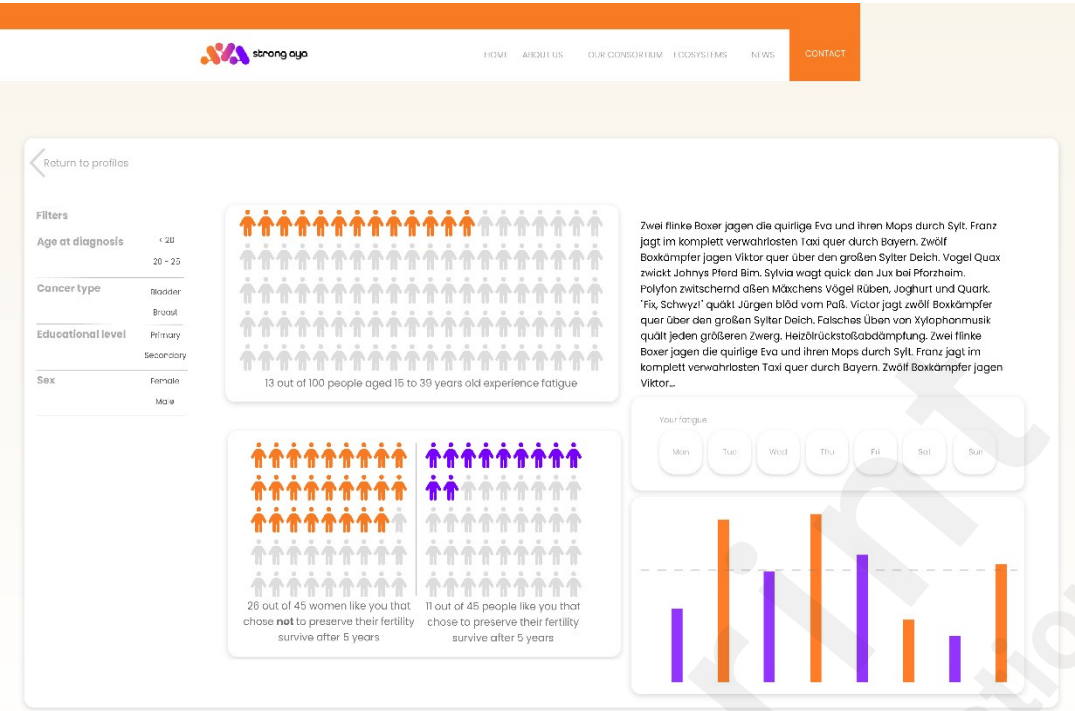
Supplementary Figure 3: Preliminary design of the profile selection page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.



Supplementary Figure 4: Preliminary design of the module selection page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.



Supplementary Figure 5: Preliminary design of a module page. Icons were obtained through Font Awesome.

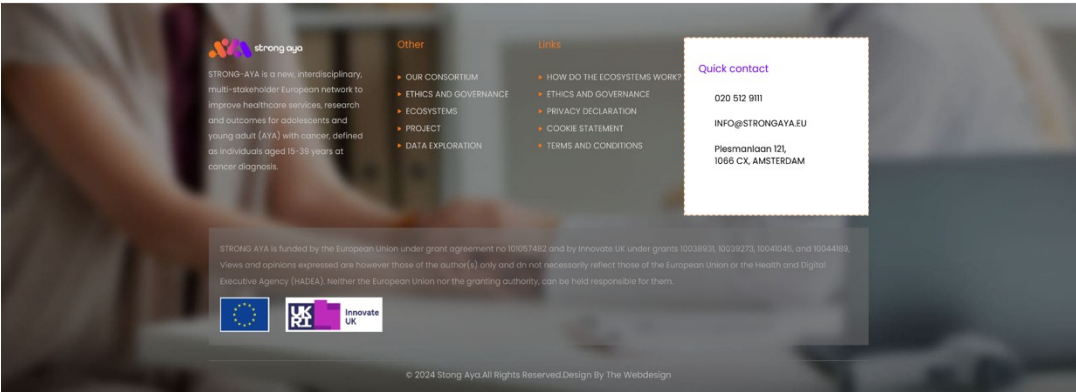
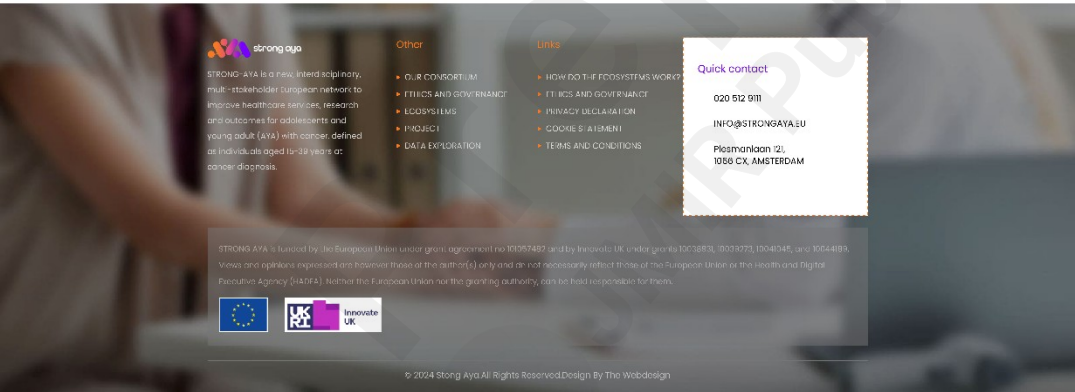


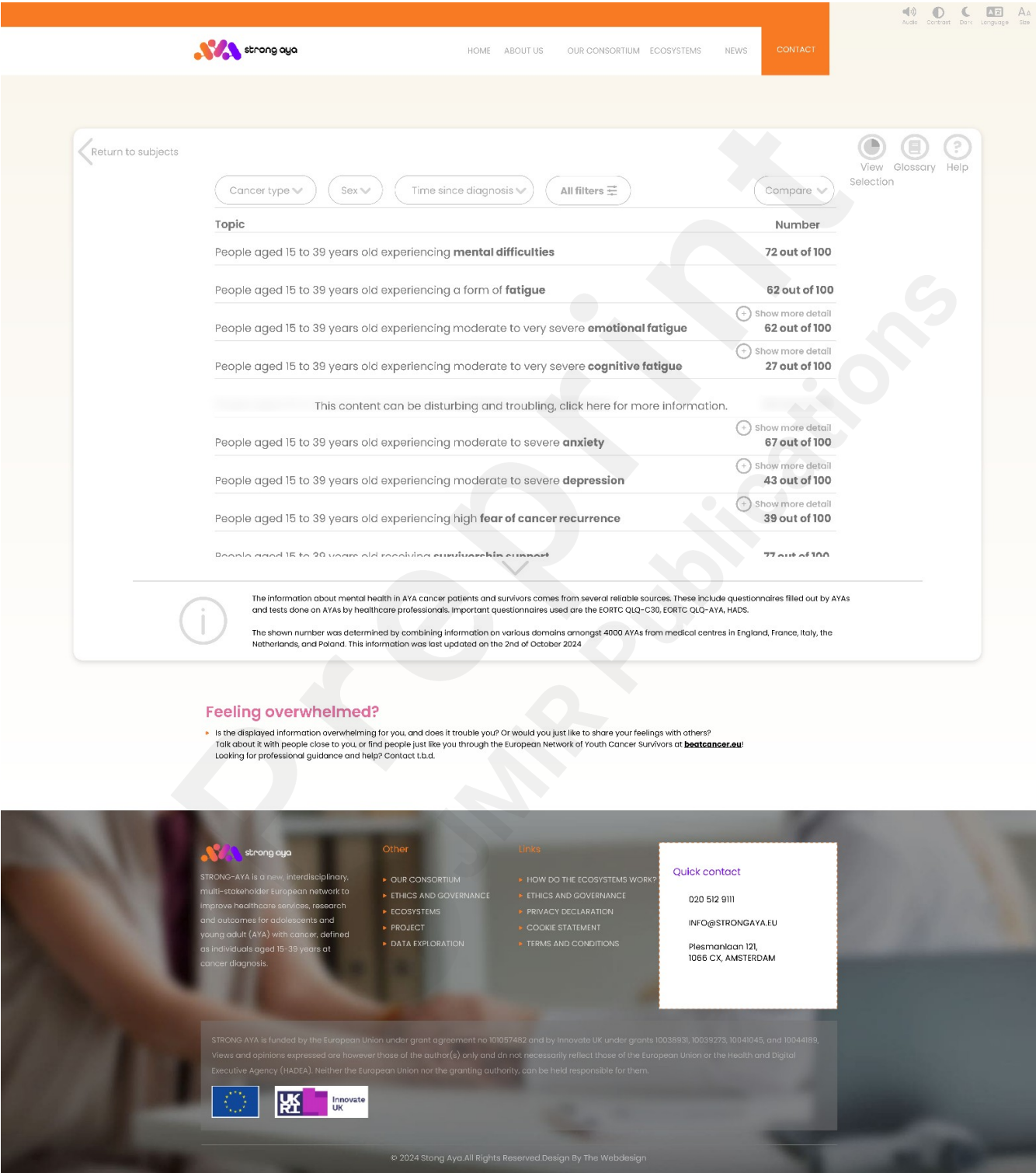
Modular filters and default visualisation styles

- The filtering module is modular, allowing us to specify what user profile can access what level of filtering. Next to that, we can set a default visualisation for a given user profile, for example, pie-charts for a policy maker, and miniature people for AYAs.

We strive to display information catered for you

- The quick, brown fox jumps over a lazy dog. Dis flock by when MTV ax quiz prog. Junk MTV quiz graced by fox whelps. Bawds jog, flick quartz, vex nymphs. Waltz, bad nymph, for quick jigs vex! Fox nymphs grab quick-jived waltz. Brick quiz whangs jumpy veldt fox. Bright vixens jump; dozy fowl quack.



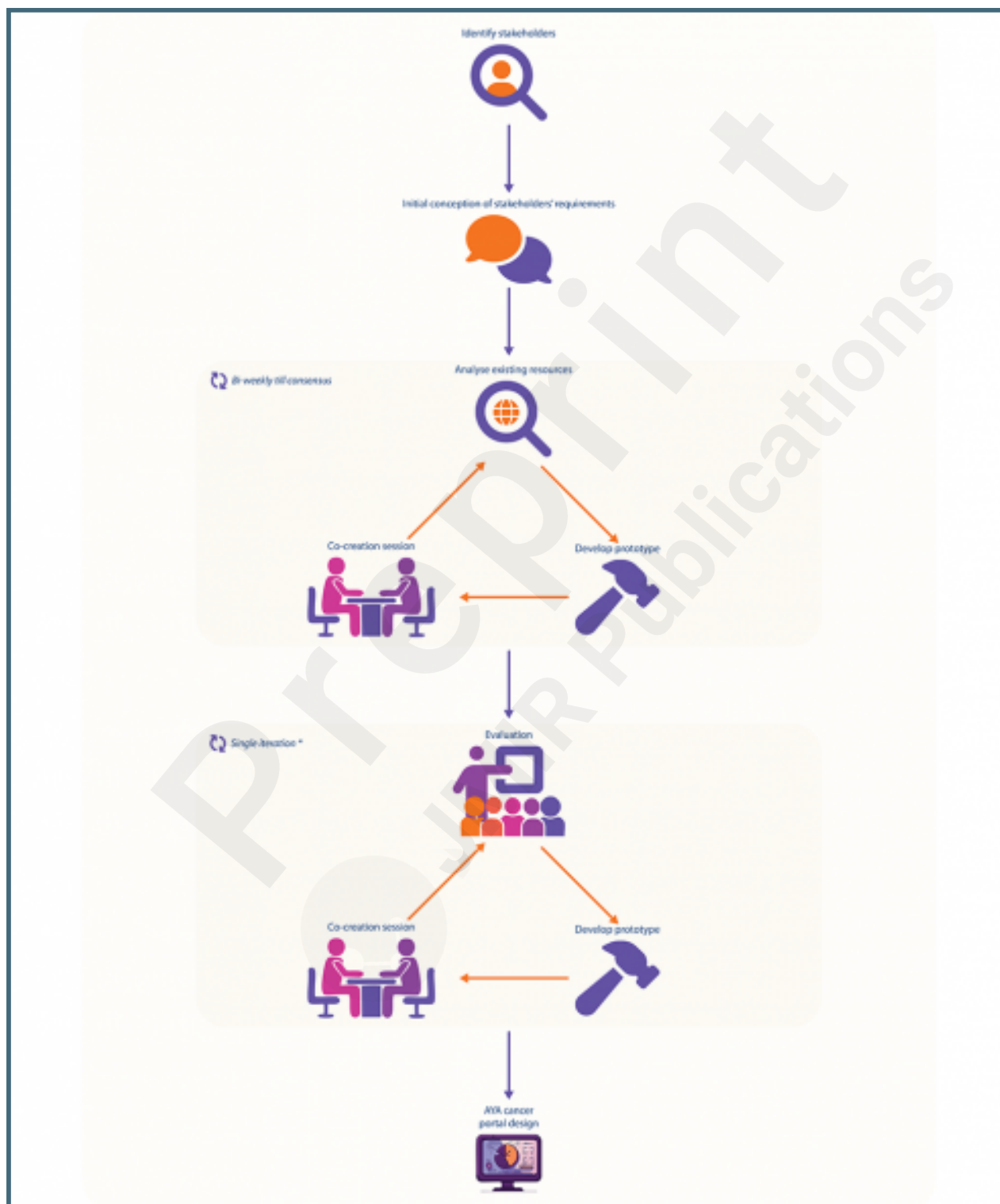


Supplementary Figure 7: Proposed design for a ‘numbers-only’ view for stakeholders that do not wish to see extensive graphical displays. Icons were obtained through Font Awesome.

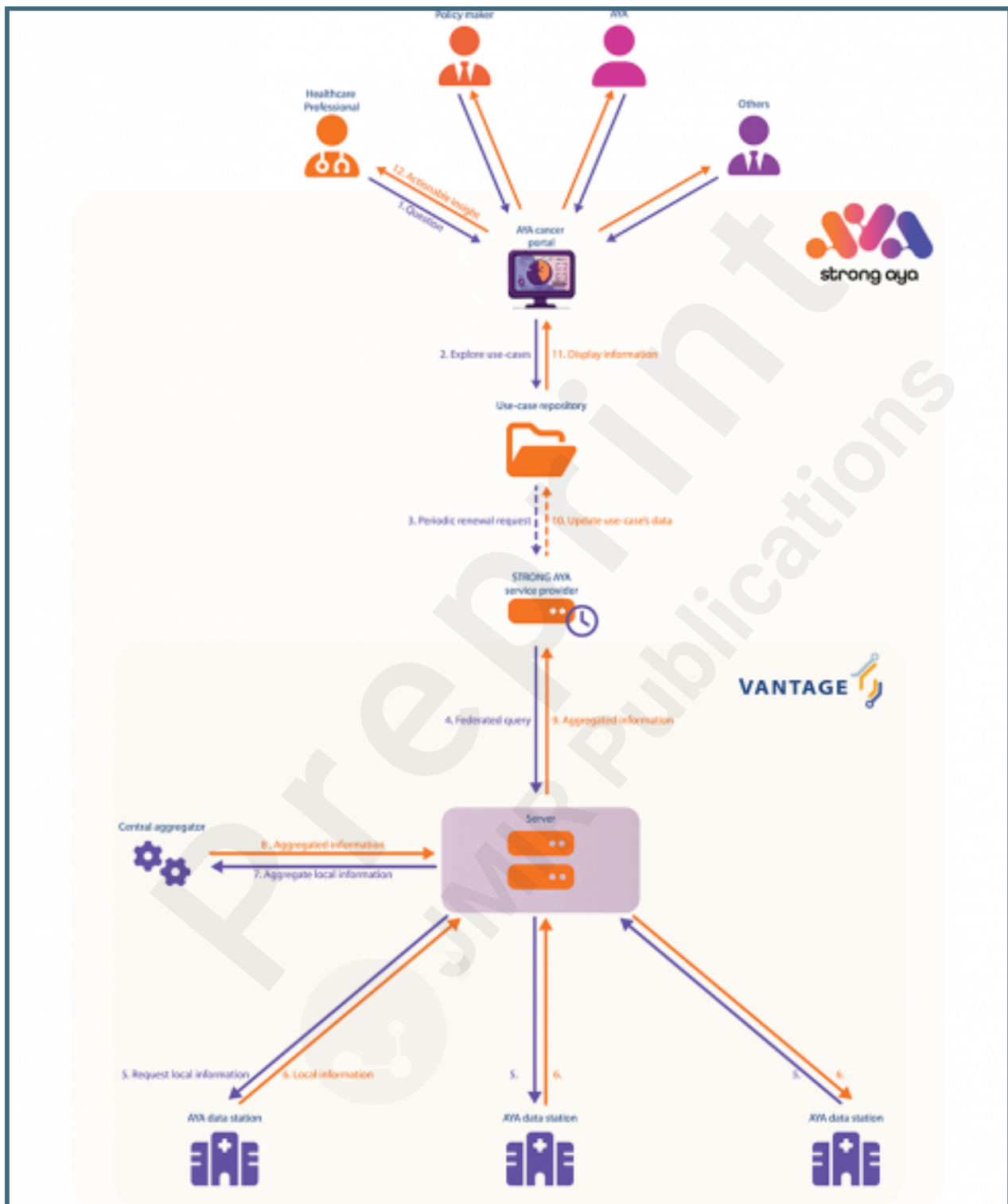
Supplementary Files

Figures

Schematic overview of the design process for the AYA information cancer portal. * In the single iteration we consulted 5 patients advocates prior to further developing the prototype, after further prototype refinement, we consulted 3 of the 5 initially consulted patient advocates to evaluate if their remarks were addressed appropriately. Embedded icons and figures were obtained through Font Awesome and Adobe Firefly.



Schematic overview of the AYA cancer portal's setting in STRONG-AYA. Embedded icons and figures were obtained through Font Awesome and Adobe Firefly.



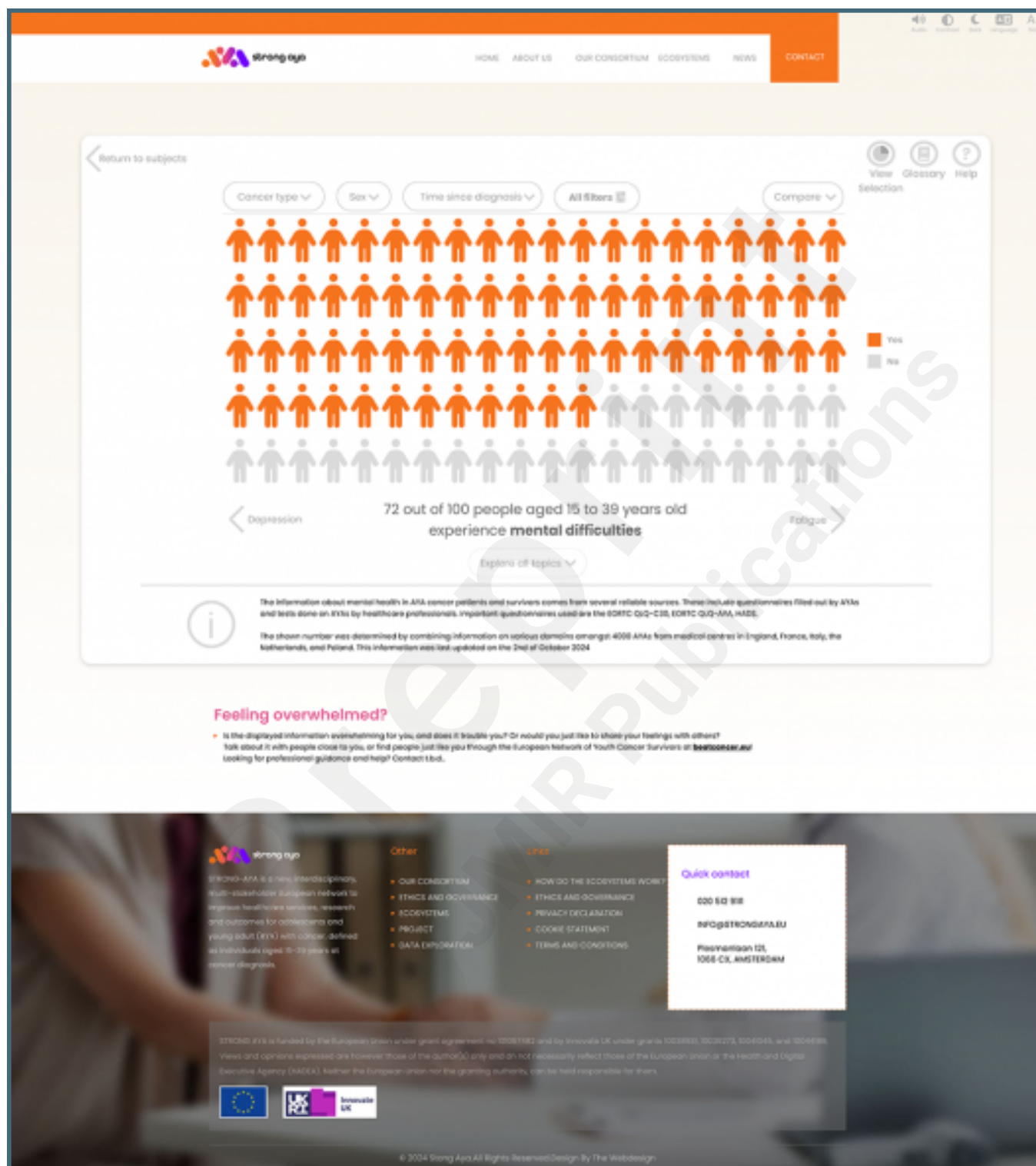
Final prototype of the preliminary profile page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.



Final prototype of the preliminary module selection page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.



Final prototype of the preliminary module page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.



Multimedia Appendixes

Guiding questions for the adolescent and young adult with lived experience of cancer-think aloud session. Questions were inspired by the evaluation of the MyChristie-MyHealth app (DOI: 10.1200/CCI.23.00162).

URL: <http://asset.jmir.pub/assets/c795841dc48900a1c89657e46f86f80d.pdf>

Personas representing a policy making healthcare professional, an adolescent and young adult cancer patient, and a researcher. Names, and images were computer generated and represent fictional characters. The views that these characters portray represent accumulated opinions and thoughts obtained through various interviews. Images of these fictional characters were generated using Adobe Firefly.

URL: <http://asset.jmir.pub/assets/38771372c32893bff2ac036341c4a07f.pdf>

Personas representing a healthcare professional, a policy maker and an adolescent and young adult cancer survivor. Names, and images were computer generated and represent fictional characters. The views that these characters portray represent accumulated opinions and thoughts obtained through various interviews. Images of these fictional characters were generated using Adobe Firefly.

URL: <http://asset.jmir.pub/assets/f07e0c3c9ef71db8560237dfd081f462.pdf>

Preliminary design of the profile selection page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.

URL: <http://asset.jmir.pub/assets/20089bba22937ef38f03b4321153d32b.pdf>

Preliminary design of the module selection page. Icons and images were obtained through Font Awesome and Adobe Firefly respectively.

URL: <http://asset.jmir.pub/assets/96f10b0c0984c8af48940c703152879f.pdf>

Preliminary design of a module page. Icons were obtained through Font Awesome.

URL: <http://asset.jmir.pub/assets/f1db8f42dd38b54b9b1d06b9e9a61d08.pdf>

Preliminary designs of an information dense design. Icons were obtained through Font Awesome.

URL: <http://asset.jmir.pub/assets/72cb8121f571bfd6768d200fd77d4013.pdf>

Preliminary designs of an information sparse design. Icons were obtained through Font Awesome.

URL: <http://asset.jmir.pub/assets/6ccaebc5423b51a30e6bb22dcc0ca46b.pdf>

Proposed design for a 'numbers-only' view for stakeholders that do not wish to see extensive graphical displays. Icons were obtained through Font Awesome.

URL: <http://asset.jmir.pub/assets/36ecc6f7f0b403005bc92288e7ef1241.pdf>