Sexuality and Intimacy Healthcare for Adolescents and Young Adults with Cancer

Ruocha Wang
"To cure sometimes.
To relieve often.
To comfort always."

- the transcendent poem widely attributed to the sixteenth-century French surgeon Ambroise Pare
Colophon

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I hope you enjoy reading this report!
Project Structure and Timeline

**Phase 1**
Exploring Current Situation
- Literature study
- Interviews with sexologists
- Interviews with AYAs
- Interviews with nurses

**Phase 2**
The Application “New Me. New We.”
- Initial ideas
- Prototype v.1
- Prototype v.2
- Prototype v.3
- Final concept design
- Design implementation
Phase 1 Exploring Current Situation

What does the big picture look like?

How does cancer affect AYAs? What impact do sexuality and intimacy have on AYAs’ well-being? How to address sexuality and intimacy care? What are the resource and referral pathway? Based upon literature and interviews with sexologists and nurses, these topics were discussed.

What are AYAs’ unmet needs?

What are the unmet needs in sexuality and intimacy care and how is AYAs’ life affected? Based on literature and interviews with AYAs, ten unmet needs were discussed in depth.

Design decisions

The core message, structure and content, as well as the form of the design are decided upon the key findings in phase 1.

Phase 2 The Application “New Me. New We.”

Concept development

Design process of the application “New Me. New We.” from ideation to iteration and the final concept. The prototypes were reviewed with AYAs, sexologists, oncology nurses, and the Dreamteam.

Final design

The final design is shown, including the mobile application design and website design. It also discusses the design implementation plan.

Conclusion

General conclusions of the research and design process and discussion for further development.
Abstract

Adolescents and young adults (AYAs) with cancer, aged from 15 to 39 years, are making the transition from childhood to adulthood. When the burden of cancer is added, it becomes part of this extraordinary and challenging time in their growth and development. Cancer affects the psychosexuality of AYAs as well as intimate relationships, which in turn influences their well-being. However, the discussion on sexuality and intimacy is hard to initiate, and AYAs are not satisfied with the information provided by the healthcare providers.

The project looked into the big picture of sexuality and intimacy care for AYAs in the Netherlands and the unmet needs of AYAs. Based on the research findings, the design concept is developed. It is an online application together with a website. To tackle the problem of insufficient discussion, the application gives information about the disturbances and prepares AYAs to initiate the discussion with their healthcare providers. For AYAs’ dissatisfaction with the information supplied, the project looked into AYAs’ unmet needs and constructed an information architecture that covers their needs.

Literature study and interviews were conducted in the research phase. The design phase implemented iterative design and human-centred design approaches, where AYAs were kept at the heart in the process.
# Table of Contents

1 Domain ................................. 2
1.1 Assignment and context .... 3
1.2 Scope ............................... 4
1.3 Methods ............................ 5

2 The Big Picture ....................... 6
2.1 How cancer affects AYAs .... 7
2.2 Sexuality, intimacy and well-being 11
2.3 Addressing sexuality and intimacy care 13
2.4 Resource and referral pathway 18
2.5 Summary ........................... 22

3 AYAs’ Unmet Needs ................. 24
3.1 Unmet needs in sexuality care 25
3.2 Interviews with AYAs ....... 26
3.3 Summary .......................... 31

4 Design Decisions ..................... 32
4.1 Review of research findings 33
4.2 Design Decisions ............... 34

5 Concept Development .............. 36
5.1 Initial ideas ....................... 37
5.2 Prototype iteration ............ 38

6 Final Design ........................ 48
6.1 The mobile application ...... 49
6.2 The website ...................... 55
6.3 Design implementation .... 58

7 Conclusion .......................... 60
7.1 Conclusion ....................... 61
7.2 Next steps ....................... 61

References ............................ 62

Appendices ............................ 68
Appendix A AYAs’ contact with healthcare providers 69
Appendix B Quotes from interviews with AYAs ... 72
This chapter discusses the assignment and context of this project, the scope of the project, and the methods used in the research and design process.
1.1 Assignment and context

“AYA” stands for Adolescents and Young Adults (AYAs) with Cancer diagnosed at the age between 15 and 39 years old. This project is supported by the National AYA ‘Young and Cancer’ Platform. The “umbrella” project, “Normalizing ‘Intimacy and Sexuality’ for and by the AYA - Developing a Toolbox for AYAs”, investigates the shortcomings of the current care for AYAs around sexuality and intimacy and seeks to improve it. It is a collaboration between the Department of Urology of the Leiden University Medical Center (LUMC), TU Delft Faculty of Industrial Design Engineering and the “Dreamteam Sexuality and Intimacy” (referred to as “the Dreamteam” in the report) formed by the National AYA “Young and Cancer” Platform.

The assignment was to design a patient-centred concept that facilitates the conversation on sexuality and intimacy for AYAs, and to provide them with information at the right time in the right way. It has two focuses: communication and information.

AYAs, aged from 15 to 39 years, are making the transition from childhood to adulthood. When the burden of cancer is added, it becomes part of this extraordinary and challenging time in their growth and development. They are also unique in the types of cancers that they develop and present problems that neither pediatric nor adult-treating oncologists are fully comfortable in managing (Bleyer, Barr, Ries, Whelan, J., & Ferrari, A. (2017). Cancer in Adolescents and Young Adults (2nd ed., p. ix). Cham: Springer).

Although impacts of cancer diagnosis and treatment is widely recognized and have been investigated in multiple studies (Olsson, Steineck, Enskär, Wilderång & Jarfelt, 2018; Dobinson et al., 2016; Wettergren et al., 2016; Acquati et al., 2017; Husson et al., 2017; Geue et al., 2013), these studies did not focus on possible solutions to minimize the negative effects.

The project is a design concept of an online application and a website for sexuality and intimacy care for AYAs. It addresses two core problems in the current care, namely the insufficient discussion between AYAs and healthcare providers and AYAs’ dissatisfaction with the information supplied. The research outcomes in phase 1, including the big picture of sexuality and intimacy care for AYAs in the Netherlands and the unmet needs of AYAs, are the foundation for the design of the application in phase 2.

The goal of the design is to lower the barrier for AYAs in exploring information and resource for the disturbance they face around sexuality and intimacy matters. It hopes to fill the information gap, and guide AYAs toward the right support.
1.2 Scope

Who?

The primary users are AYAs. The project looks at AYAs in all possible phases of the cancer journey, including rehabilitation, palliative phase and survival phase.

AYAs’ (future) partners and the healthcare providers that they have contact with can also benefit from the design. However, within this graduation project, the focus is to support AYAs. Further research and adaptation are needed if they are to be included as formal users.

The main stakeholders include AYAs and (future) partners, oncologists, urologists, gynaecologists, (oncology) nurses, sexologists and the National AYA “Young and Cancer” Platform. There will be an expert team composed of physicians and practitioners who complete and regularly update the content. The author of this report and the National AYA “Young and Cancer” Platform will promote the project together.

What?

Cancer affects the psychosexuality of AYAs as well as intimate relationships, which in turn influences their well-being. Sexuality and intimacy care is important in the overall healthcare for AYAs, but the discussion is hard to initiate, and the AYAs are not satisfied with the information provided by the healthcare providers.

Where?

The setting can be a home environment, chemotherapy room in the hospital, etc., where AYAs feel comfortable interacting with a digital application about sexual health.

Why?

AYAs not asking for more information has mostly to do with feelings of shame and not knowing whom to ask. For healthcare providers, the lack of training is the major hindrance to discussions on sexual health. Both parties have difficulties taking the first step of the discussion.

When?

The design solves existing problems based on the current situation and available resource of sexuality and intimacy care in the Netherlands. It provides in-time support for AYAs along their cancer journey.

How?

The discussion between AYAs and healthcare providers does not happen easily and does not always meet the needs of AYAs. The design gives AYAs basic information about their disturbances (which replaces the conversation) and when necessary, prepares them for a constructive discussion before they approach healthcare providers.
1.3 Methods

**Literature study**

The national cross-sectional survey about sexuality and intimacy among AYAs in the Netherlands conducted by the National AYA ‘Young and Cancer’ Platform (Haj Mohammad, 2019) was the starting point, and the result was analyzed in collaboration with researchers from LUMC to explore appropriate concepts for AYAs. Two books, *Cancer, Intimacy and Sexuality - A Practical Approach* (Reisman & Gianotten, 2017) and *Cancer in Adolescents and Young Adults* (Bleyer, Barr, Ries, Whelan & Ferrari, 2017) were the primary source of reference. Other literature about roles of different healthcare providers, psychoeducation and the sexual healthcare intervention model, etc., were also studied.

**Interview**

Findings from interviews were important to the design iteration. In total, there were five interviews with two sexologists, two interviews with two oncology nurses, seven interviews with five AYAs and continuous email contact with them, one meeting with the “Dreamteam Sexuality and Intimacy” and one meeting with the AYA team in Singapore in the preparation stage of the project. All interviews were recorded and transcribed. Prototypes were shown to interviewees to generate discussions and receive feedback. Q-sort method (Brown, 1996), a popular qualitative research approach, was used to understand the unmet needs of AYAs, with questionnaire as a follow-up. With sexologists and oncology nurses, the content and structure of the application were discussed.

Pseudonyms are used in the report to respect the privacy of the AYAs interviewed. They are referred to as AYA Anne, Emma, Lisa, Daan and Leon.

**Iterative design and human-centred design**

The design process followed the classical iterative design methodology with the cyclic process of prototyping, evaluating, analyzing and refining. Meanwhile, with the human-centred design approach, AYAs were at the heart of the design process. Empathy with AYAs enabled deep understanding of their needs, from which many opportunities for design were identified. The prototypes were reviewed with AYAs and sexologists and oncology nurses who had extensive contact with AYAs.

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2 The Big Picture

This chapter discusses four topics to give a view of the big picture: how cancer affects AYAs; sexuality, intimacy and well-being; addressing sexuality and intimacy care; and resource and referral pathway. This chapter lays foundation for the solution to better communication between AYAs and healthcare providers.
2.1 How cancer affects AYAs

2.1.a The Biopsychosocial Model

AYAs are experiencing the transition from childhood to adulthood while handling the burden of cancer. The influence of cancer on AYAs is beyond biological. To have an overview of how cancer affects AYAs, the Biopsychosocial Model, a general theory of illness and healing, was applied. The Biopsychosocial Model, developed by Engel in 1977, is an interdisciplinary model that looks at the interconnection between biology, psychology, and socio-environmental factors. It is a way of understanding the patient’s subjective experience as an essential contributor to humane care (Borrell-Carrio, Suchman & Epstein, 2004).

A quote from a British healthcare coach who is also a patient explains the importance of the multifaceted consideration in providing care for patients: “The medical support keeps me alive, but it is the psychological and social support that enables me to live (de longh, 2013).”

Based on two books, Cancer, Intimacy and Sexuality - A Practical Approach (Reisman & Gianotten, 2017) and Cancer in Adolescents and Young Adults (Bleyer, Barr, Ries, Whelan & Ferrari, 2017) and the general understanding of illness, a Biopsychosocial Model for AYA is drawn in figure 1.

**Biological level**

The biological influence factors include cancer itself, chemo/radiotherapy, medication, surgery, etc.

Regarding the body, the disturbances include body pains, nerve damage, altered body image, fertility issues, baldness, pelvic fibrosis (female), fatigue, nausea, bowel/bladder function change, somatisation, hormone imbalance, etc.

Regarding the sexual organ, the disturbances include: bleeding/pain during/after sex, hot flashes (male/female), urine leak (male), ejaculatory pain (male), erectile dysfunction (male), lower lubrication (female), no more/shorter vagina (female), disturbance of period (female), etc.

Regarding sensation, the disturbances include: less sexual desire, loss of sex pleasure, altered/loss of sensation, delayed/difficulty with orgasm, changed skin feeling, painful sensation, numbness, etc.

**Psychological level**

The psychological influence factors include coping skills, attitude and belief, new normalization and meaning finding process, etc.

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The disturbances include anxiety/depression, self-uncertainty, reduced self-esteem, reduced self-confidence, altered masculinity/femininity, emotional lability, scared to disappoint partner, fear around intimacy, reluctance/fear of disclosure, etc.

**Social level**

The social influence factors include social/family/partner support; socioeconomic status, etc.

The disturbances include loss of independence, limited lifestyle option, removal from the social context, removal from peer network, reduced autonomy, less dating opportunities, changed parenthood, altered relationship formation, compromised future goals, etc.

The Biopsychosocial Model provides an overall view of the disturbances AYAs may face and their influence factors. It helps us understand the interconnection between issues on different levels. For example, “reduced self-esteem” and “scared to disappoint partner” (psychological) may be caused by “altered body image” (biological) from the removal of breast for breast cancer AYAs, and therefore result in “altered relationship formation” (social). If it is the case, then helping the AYA think about “reconstruction surgery” (biological), working on “new normalization” and “coping skills” for accepting the new body (psychological), and providing couple therapy on communication (social) in the relationship are possible ways to support the AYA with these disturbances.

### 2.1.b Common cancer types among AYAs

Based on the data extracted from the November 2011 submission for Surveillance, Epidemiology, and End Results (SEER) registration in the US, Lewis, Seibel, Smith & Stedman listed the incidence rates of different types of cancer by age at diagnosis.

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Leukemias</td>
<td>6.99</td>
<td>3.19</td>
</tr>
<tr>
<td>Lymphomas (HL and NHL)</td>
<td>17.13</td>
<td>8.58</td>
</tr>
<tr>
<td>All CNS</td>
<td>6.27</td>
<td>3.13</td>
</tr>
<tr>
<td>Osseous sarcoma</td>
<td>2.22</td>
<td>1.00</td>
</tr>
<tr>
<td>Soft tissue sarcoma</td>
<td>4.61</td>
<td>2.85</td>
</tr>
<tr>
<td>Germ cell and trophoblastic neoplasms</td>
<td>20.96</td>
<td>1.32</td>
</tr>
<tr>
<td>Melanoma and skin carcinomas</td>
<td>11.30</td>
<td>11.59</td>
</tr>
<tr>
<td>Thyroid carcinoma</td>
<td>5.28</td>
<td>16.52</td>
</tr>
<tr>
<td>Carcinoma of breast</td>
<td>0.11</td>
<td>24.37</td>
</tr>
<tr>
<td>Carcinoma of colon and rectum</td>
<td>6.94</td>
<td>11.05</td>
</tr>
<tr>
<td>All other carcinomas and misc. and unspecified neoplasms</td>
<td>18.38</td>
<td>12.50</td>
</tr>
<tr>
<td>Total</td>
<td>100.00</td>
<td>100.00</td>
</tr>
</tbody>
</table>

* CNS = central nervous system; HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma.
Below lists the cancer types with the highest incidence rates for male and female AYAs. For better classification and easier understanding of the design, there were some minor changes made to the terminology. For example, “osseous sarcoma” and “soft tissue sarcoma” were combined as “sarcoma”, and “carcinoma of breast” was written as “breast cancer”.

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2.1.c The cancer trajectory

- **Before Diagnosis**
  - fatigue - diminish sexual desire and flexibility
  - fear for cancer - change sexuality
  - worry - diminish/increase sensual/sexual contact

- **Diagnosis**
  - overwhelming emotions - shock, fear, insecurity, confusion, and sometimes anger - some immediately stop anything physical, others have increased intimate contact

- **Decision Phase**
  - a wide range of emotional setups - can be scared for a specific treatment, different opinions on the meaning of life versus the meaning of quality of life

- **Treatment**
  - fear and solitude for patient and partner
  - additional burden for the partner
  - happiness when everything is past

- **Rehabilitation**
  - face the damage - emotional damage, physical damage and side effects, sexual or relationship damage
  - new balance to be found

- **Survivor**
  - fear, stress and insecurity
  - possible long-term health consequences - cardiomyopathy, neuropathy, infertility and increased risk of developing second cancer
  - things lost in previous phases - sense of invulnerability and immortality, appearance and youth, fertility, partner, stamina, sexual capacities

- **Palliative**
  - continue life as good as possible
  - physical aspects - result in cessation of sexual activity
  - impact on sexual identity of the patient and on the relationship - e.g. no longer feel sexually attractive

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Reisman & Gianotten listed the seven phases of the cancer trajectory and discussed the main sexual consequences in each phase. A summary of sexual consequences regarding AYAs (and their partners) in each phase is shown in figure 4.

In an interview with Dutch sexologist Woet Gianotten on 1st April 2019, the possible interventions throughout the cancer trajectory were discussed.

**Diagnosis Phase**

**Screening**: To look at both the social system of the patient and his/her sexual and relationship baseline. These are important references for future intervention.

**Decision Phase**

**Integration**: To integrate sexual health intervention within AYA care by making sexual function, sexual identity and sexual relationship “talkable”.

**Treatment Phase**

**Informing**: To inform the patient - What will/could happen in sexuality and intimacy. Why?

**Education**: To educate the patient - How to deal with that? The emphasis is that after the treatment, pleasure and intimacy are still possible.

**Asking**: To regularly ask about the patient’s life - How are you?

**Rehabilitation and Survivor Phase**

**Education**: To educate the patient - How to adapt? How to create? The emphasis is that real health is not the absence of disease, but the skill to properly deal with what is available.

**Asking**: To regularly ask about the patient’s life - How are you?

**Palliative Phase: Screening**

**Awareness**: To have the awareness that patients may need professional advice and support regarding their sexual activity.

**Asking**: To regularly ask about the patient’s life - How are you?

These interventions were used to inspire the design of different functions and contents of the application.

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**Finding 02**

Disturbance in sexuality and intimacy can appear in every phase of the cancer journey. Different types of interventions are needed.

2.2 Sexuality, intimacy and well-being

2.2.a Insights from the national survey

The national cross-sectional survey about sexuality and intimacy among AYAs in the Netherlands was conducted by the National AYA ‘Young and Cancer’ Platform in 2018 among 56 AYAs, with a mean age of 29.4 (Haj Mohammad, 2019).

AYAs reported unmet psychosexual needs. Three-quarter of the respondents reported sexuality-related issues as a result of cancer treatment. Information regarding these issues was considered important by 91% (Haj Mohammad, 2019).

Inadequate support from physicians and lack of information regarding sexuality-related issues may contribute to unmet needs. Nearly half of the respondents think the subject of intimacy and sexuality is not sufficiently discussed by the healthcare providers, and not asking for more information on their initiative has mostly to do with feelings of shame. Meanwhile, dissatisfaction with the information supplied mainly concerns the nature of information being not specific, healthcare provider not initiating the discussion, and the information not provided earlier.

The insights from the national survey in current care and the needs of AYAs had yet to be used to create possible innovative solutions to improve care regarding sexuality and intimacy. This project, therefore, took the step forward and designed a concept that addresses the two core problems in the current care, namely the insufficient discussion between AYAs and healthcare providers and AYAs’ dissatisfaction with the information supplied.
2.2.b Importance of sexuality and intimacy care

The number of AYAs diagnosed in 2018 worldwide was estimated to be over 1.2 million (Cancer Today - IARC, 2018). In Europe and North America, 5 year survival rates above 80% were well recorded in the AYA population (Barr, 2011). With rising long-term survival-rates for cancer, quality of life, including sexual health, is becoming increasingly significant (Krouwel et al., 2015).

Sexual health is defined as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity (World Health Organization, 2006)”.

Cancer, diagnosis and treatment can affect the psychosexuality of AYAs in terms of psychosexual formation, sexual functioning and sexual needs (Trama et al., 2016). It also impacts their intimate relationships from evolvement (Trama et al., 2016) to sustainment of the relationship (Zebrack, 2011).

Psychosexuality needs and intimate relationships influence the well-being of AYAs. Dobinson et al. suggest that unmet psychosexual needs could negatively affect the quality of life if these needs are neglected (2016). Intimate relationships are of key importance in coping with the disease and satisfying these relationships contribute to psychological acceptance and recovery of the patient (Geue, Schmidt, Sender, Sauter & Friedrich, 2015; Robinson, Miedema & Easley, 2014).

Figure 6 shows a summary of the impact of cancer on the psychosexuality of the AYAs and intimate relationships and their influence on the well-being of AYAs.
2.3 Addressing sexuality and intimacy care

2.3.a Barriers to discussions

Surgery, chemotherapy, hormonal agents, radiation therapy, intrinsic disease and psychological disease-related or body image factors may all contribute to a decrease in sexual function (Krouwel et al., 2015). It is important for healthcare providers to inform patients on sexual side effects and detect if a patient is experiencing any problems (McKee & Schover, 2001).

An essential way for AYAs to be supported in sexuality and intimacy care is through interaction with healthcare providers. However, it is frequently not addressed by oncology health care providers (Flynn et al., 2010). Within a study on possible omissions regarding attention paid to sexual function in oncology care in the Netherlands, three papers that revealed the barriers to discussions about sexuality and intimacy. They looked at the role that the oncology nurses, radiation oncologists and surgical oncologists played when addressing sexual concern, side effect or sexual functioning.

**Oncology Nurses**

According to the research conducted by Krouwel et al. in 2015, oncology nurses are strategically placed to address sexual function since they have frequent patient interaction. Based on the responses from oncology nurses, the most agreed barriers for them in discussing sexual function in relation to AYAs are “lack of training” (42%), “presence of a third party” (41%), “no angle or motive for asking” (32%). “Patient is too ill” (29%), “lack of knowledge” (25%) and “patient doesn’t bring up the subject” (22%) are also among the most agreed barriers. “Culture/religion” and “language/ethnicity” are also important barriers.

**Radiation Oncologists**

Another research about radiation oncologists regarding sexual counselling after (pelvic) radiotherapy (Krouwel et al., 2015) shows that the most agreed barriers for them are “patient is too ill” (36%), “no angle or reason for asking” (32%), “sexuality is not a patient’s concern” (24%), “patient does not bring up the subject” (20%) and “lack of training” (19%). “Culture/religion” and “language/ethnicity” are also important barriers.

**Surgical Oncologists**

As for surgical oncologists, when it comes to managing sexual side effects in the surgical oncology practice (Krouwel et al., 2015), the most agreed barriers are “not relevant for all type of cancers” (44%), “lack of time” (40%), “no angle or motive for asking” (35%), “lack of training” (33%), “patient doesn’t bring up the subject” (32%), “presence of a third party” (26%) and “surviving is more important” (24%). “Culture/religion” and “language/ethnicity” are also important barriers.

Interestingly, 86% of surgical oncologists stated that discussing sexual function is their responsibility, but 37% of them never or rarely discuss sexual health with their patients. For oncology nurses, 88% see it as their responsibility and 19% never or rarely address. For radiation oncologists, in palliative cancer care, 80% of them never discuss sexual functioning with the patient, and 20% rarely do.

“Culture/religion” and “language/ethnicity” were beyond the main scope of this project. As sexuality is a culturally sensitive topic, users who are more conservative about sex should feel comfortable using the application as well. The language level was considered when designing the
content of the app, for example, “baldness” is used in the content of the application instead of “alopecia”.

The three types of professions share similar barriers in addressing sexual health. Figure 7 summarises the common barriers for oncology nurses (the pink figures), radiation oncologists (the blue figures) and surgical oncologists (the green figures) besides “culture/religion” and “language/ethnicity”. The size of the figures reflects the percentage of respondents who agreed with each barrier.

As suggested in the three papers, there are potential benefits of providing educational and practical training, composing a list for specialised referral, developing a complete department protocol and raising awareness (Krouwel et al., 2015; Krouwel et al., 2015; Krouwel et al., 2015).

Given the increasing pressure in the daily practice of healthcare providers and the multiple intrinsic barriers, this project did not intend to intervene with the current practice of healthcare providers. Instead, the project focused on psychoeducation of the AYAs so that either their concerns are explained by the application, or they are prepared to bring up the topic themselves and ask specific questions to the right healthcare provider. This will be explained further in the next sections.

Finding 04
Oncology nurses, radiation oncologists and surgical oncologists share similar barriers in addressing sexual health.


Figure 7. Common barriers in addressing sexual health for oncology nurses, radiation oncologists and surgical oncologists.
In order to understand the interaction between the AYAs and the healthcare providers when sexuality and intimacy care is (not) provided, and why sufficient discussion is lacking, the commonly used PLISSIT framework in clinical practice was studied. It was used to analyze the current problem in sexuality and intimacy care and to find design opportunities for the project.

The widely used Permission (P), Limited Information (LI), Specific Suggestions (SS), and Intensive Therapy (IT) (PLISSIT) model was developed by Jack S. Annon, an American clinical psychologist in 1976 (Annon, 1976) for the purpose of introducing sex into a clinical conversation. The four levels of intervention included in the model range from basic to complex. It guides clinicians to support patients according to the unique needs of individual patients as well as the clinician’s own comfort level and expertise. Referrals can be made when a patient’s needs exceed a clinician’s comfort, knowledge, and time (Clinical Tool: The PLISSIT Model, 2019).

The Whole Health Education program at University of Wisconsin-Madison summarized the four levels of intervention as follows:

**Permission (to Discuss)**

Giving permission to or asking permission from your patients - permission to discuss feelings and concerns related to a specific health issue that they may be hesitant to discuss.

**Limited Information**

Helpful to some patients (beyond permission level). Providing basic education about the topic at hand. It requires some knowledge about the specific topic to answer patients’ questions and dispel misconceptions. Factual information in patient handouts and a list of resources (e.g., holistic practitioners) may be helpful.

**Specific Suggestions**

Required by fewer patients. Requires advanced knowledge of a particular health issue and skill to assess a patient’s unique situation related to this health issue and to develop a plan.

**Intensive Therapy**

Required by a minority of patients for a particular issue. This fourth level of intervention may require referral to a specialist (Clinical Tool: The PLISSIT Model, 2019).

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**Figure 8. The PLISSIT model of addressing sexual health (Annon, 1976).**

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For the context of this project, the four levels of intervention for AYAs (and partners) may appear in the ways below. It does not necessarily need to be a face-to-face appointment. The intervention can also be done through interaction in an online application.

**Permission (to Discuss)**

“I know having cancer at this age is really something different. Sexual health is an important part of quality life. Is there any concern you’d like to discuss?” or “It is not right for people to assume that teenagers don’t need support in sexual health. You are entering adulthood and it is hard when you also have to deal with cancer. If you have any thoughts, I am here to listen. Anything.”

**Limited Information**

“Indeed your chemotherapy is affecting the function of the vagina, and dryness is a common side effect. But it’s only temporary, and there are some simple things you can do to make it better.”

**Specific Suggestions**

“Having pain during sex doesn’t mean sex is not for you anymore. There are ways to deal with it. Pelvic floor rehabilitation might be helpful. I can refer you to a pelvic rehab practitioner, and together we will make a practical plan for you.”

**Intensive Therapy**

Individual counseling about rehabilitation techniques with physiotherapist; couple therapy about sexual communication with sexologist.

The PLISSIT model helped further analyze the barriers discussed in the previous section.

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Finding 05

Most barriers in addressing sexual health appear in the first layer of intervention, permission (to discuss), which may stop the discussion from happening in the first place.

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Figure 9. Communication barriers in each level of sexual health intervention.
Figure 9 summarises the barriers in each layer of intervention during an appointment. It is clear that most barriers appear in the first layer, Permission (to Discuss), which may stop the discussion from happening in the first place. Moreover, when the first layer is completed, some patients may need further intervention besides information giving, but the healthcare providers might lack knowledge in these further interventions, leaving some problems unsolved.

**Crossing barriers in the first layer**

To cross the barriers in the first layer, there needs to be a new way to initiate the discussion. Given the nature of the stressful daily routine of healthcare providers, it is not easy to directly add in the sexuality and intimacy care part in their practice. But they do have the resource within and outside the hospital to support the patient’s sexual health. For example, they can write referrals, or know which organisation is reliable if the patient wants to participate in an activity. Therefore, the solution of the project focuses on the AYAs. Through psychoeducation, the permission layer is first done within the application. AYAs are reassured that seeking support in sexual health is an appropriate action for their situation, the issue they face is a legitimate health matter, and that they can take an active role in improving their quality of life. The desired outcome is that either their concerns are explained by the application, or they are prepared to bring up the topic themselves and ask specific questions to the right healthcare provider.

**Crossing barriers in the later layers**

To cross the barriers in the later layers, training and knowledge are essential. Of course, the healthcare providers are not expected to be “walking encyclopedias” of all the explanation and solution. There are many specialised experts in the Dutch healthcare system for different problems that AYAs (and partners) may face. For example, there are 339 registered sexologists/doctors/healthcare psychologists. Within 15 km from TU Delft, there are 30 experts with different specialisations who can help with sexology problems (“Zoek een seksuologisch hulpverlener”, 2019). Take sexology support as an example, the main barrier is that sometimes the healthcare providers “don’t know their (the sexologists) existence (Beekman, 2019)”. Therefore, if the AYAs are already aware of an expert who can help, directly asking if a referral can be made can help cross the barrier too.

**Crossing the barrier “lack of knowledge”**

Meanwhile, lack of knowledge as a major barrier and healthcare providers need support too. Although medical students receive sexology training, it is relatively short, and they do not always remember well after the training (Beekman, 2019). The design can serve as a communication tool when AYAs and healthcare providers discuss sexual health matters. From the AYAs’ perspective, and with the healthcare provider’s knowledge of the healthcare system, they can look for resources and find referral pathway together. In addition, when the healthcare provider knows how to reach support after the permission layer, he/she is more willing to discuss sexuality and intimacy. For example, the oncologists at LUMC discuss it more easily knowing there is a good sexologist at LUMC to work together with (Dreamteam Sexuality and Intimacy, 2019).
2.4 Resource and referral pathway

2.4.a AYA care in Dutch hospitals

Interviews with two sexologists, two oncology nurses and five AYAs addressed the available resource in the Netherlands that supports sexuality and intimacy care for AYA and referral pathways for patients.

There are seven University Medical Centers (UMCs) in the Netherlands. They all have an AYA team that offers complex AYA care. Amsterdam UMC and UMC Groningen are very strong in AYA care, LUMC, UMC Utrecht and Erasmus MC are relatively strong, and Radboud UMC and Maastricht UMC+ are still improving in AYA care (Gianotten, 2019). As can be seen from figure 10, not all regions in the Netherlands have good access to AYA care.

Over half of the AYAs in the Netherlands receive their treatment in the UMCs. While for follow-ups, it is mostly done in the general hospitals (Swinkels, 2019). There are 13 general hospitals with an AYA contact person who offers basic AYA care and other general hospitals without an AYA contact person.

As mentioned above, oncology nurses are strategically placed to address sexual function (Krouwel et al., 2015), but not all UMCs have enough nurses specialised in oncology, or AYA care specifically. At UMC Groningen, there are eight nurses in the outpatient unit who can address AYA care individually, and it is part of the regular routine for the nurses to make appointments with AYAs as soon as they are diagnosed (van Essen, 2019). At Radboud University Medical Center in Nijmegen, there was limited AYA support in connection with AYA’s age and specific disturbances, as mentioned by interviewee AYA Lisa.

Moreover, not all AYAs receive support on sexuality and intimacy from AYA teams. It is because most of the problems occur after the treatment. At that time the AYAs have left the UMCs, and the healthcare providers in general hospitals usually don’t know about the AYA teams (Swinkels, 2019). Therefore, it is important to make AYA teams at UMCs known to the healthcare providers and patients. It is always possible to refer the patients back to the UMCs for sexuality and intimacy care (Swinkels, 2019).

AYA Lisa. (2019). Reviewing the design prototype of New Me. New We. [In person]. Arnhem.


van Essen, H. (2019). AYA patient journey and interaction with oncology nurses [In person].

Figure 10. University Medical Centers in the Netherlands and their AYA care capabilities.
2.4.b Healthcare providers in each phase

Mapping out which healthcare provider is involved in each phase gave the project an overview of when the AYA has contact with whom. With this information, the design personalised the support for AYAs in different phases.

Figure 11 on the next page is based on the interview with sexologists and AYAs and reviewed with Senior Nurse Eefje Swinkels. Besides being a reference for the design process, this map itself can also give healthcare providers and AYAs a clearer view of the possible patient-healthcare provider interaction. Although not all healthcare providers are needed by all AYAs, it is important that they clearly know the possibility, because the solution is actually very close sometimes (Swinkels, 2019). For example, that AYAs can ask to be seen by a sexologist. AYA Lisa said in the interview “I wish I had gone to one… I never thought of it. It’s stupid, because I know they exist.” It shows how much can be missing because of a small gap in the information access.

2.4.c Referral pathway for AYAs

Mapping out the referral pathway for AYAs is important because this big picture is not always clear to everyone. Interviews with AYAs suggested that healthcare providers they met knew very well about their expertise, but giving information beyond their expertise was hard for some. In an ideal situation, the specialised AYA nurse knows all the resource in the healthcare system and can refer the AYA to any expert directly. But in reality, it’s not possible yet.

Figure 12 is based on interviews with AYAs. It shows the referral pathway of how the patient, without the support from an AYA nurse, can reach different healthcare providers and resource for sexuality and intimacy care.

The pathway excludes the healthcare providers that AYAs said they are not likely to discuss sexual health issues with, or that have limited contact with the patient, such as pathologist and geneticist. It includes non-medical specialists and useful platforms and groups. The questionnaire and response used for getting this information can be seen in appendix A.

“Primary contact” lists healthcare providers that all AYAs talk to during their cancer journey. “Continuing support” stands for the healthcare providers and resource that AYAs can be referred to if needed.

Some referrals happen more often than others. In the referral pathway, “referred physicians” like reconstruction surgeon are usually introduced to breast cancer patients by their healthcare providers in the “primary contact”. But healthcare providers of “primary contact” rarely refer AYAs to practitioners for “continuing support”, although there are experts for specific sexuality and intimacy issues, such as sexologist for sexual identity conflict and specialized therapist for cancer-induced relationship problems. AYAs need to see their existence and figure out how to reach them by themselves.

The meaning of “referral” is two-fold. On the one hand, the healthcare provider giving the referral should know how the next expertise can help. On the other hand, he/she can help arrange practical matters during the referral, like finding the expert in the neighbourhood and looking for better insurance coverage, e.g. the oncology nurse at UMCG might call the GP of the AYA and ask the GP to write the referral, so that the AYA can have therapy near home with the cost covered (van Essen, 2019).

In the design, a way to help the user find the right expert and these practical resources is an important function. It helps fill the small but crucial gap of information in the current Dutch healthcare system.

AYA Lisa. (2019). Reviewing the design prototype of New Me. New We. [In person]. Arnhem.

van Essen, H. (2019). AYA patient journey and interaction with oncology nurses [In person].
AYA Anne. (2019). Discussing unmet need of AYAs [In person]. Delft.

AYA Daan. (2019). Discussing unmet need of AYAs [In person]. Utrecht.

AYA Emma. (2019). Discussing unmet need of AYAs [In person]. The Hague.

AYA Leon. (2019). Discussing unmet need of AYAs [In person]. Haarlem.

AYA Lisa. (2019). Discussing unmet need of AYAs [In person]. Arnhem.


Figure 11. Different healthcare providers involved in different phases.
Figure 12. Referral pathway for sexuality and intimacy care.
2.5 Summary

In this chapter, four topics were discussed: how cancer affects AYAs; sexuality, intimacy and well-being; addressing sexuality and intimacy care; and resource and referral pathway. Together they gave an overall view of the big picture. Here summarizes the key findings of this chapter.

1) Multifaceted disturbances and different interventions

For the sexuality and intimacy disturbances that AYAs face, they have interconnected bio-psycho-social factors, and every phase of the cancer journey has a different situation that requires different interventions. Therefore the design looks at bio/psycho/social layers while following the possible interventions.

2) Core problems in AYA care: discussion and information

The two core problems in the current care are the insufficient discussion between AYAs and healthcare providers, and AYAs’ dissatisfaction with the information supplied. The solution for the first problem is discussed in this chapter. The second problem is discussed in the next chapter.

3) Find a new way to initiate discussion: patient’s initiative

The discussion is hard to initiate because of the many barriers shared by different healthcare providers. To bypass the barriers, patients can initiate the discussion by directly asking for support from healthcare providers of “primary contact” when they are aware of what can help in “continuing support”. Therefore the design prepares the patient toward this behavior.

4) Need to provide same AYA care resource for everyone

AYA care resource is not evenly distributed across the UMCs in the Netherlands. Moreover, most problems occur after discharge from UMCs, and general hospitals have limited knowledge about AYA care. Therefore it would be beneficial if patients can access the same sexuality and intimacy care without seeing the AYA team in UMCs in person.

5) Information gap to be filled

Knowledge of useful resource is important. It allows healthcare providers to discuss sexuality and intimacy more easily and helps AYAs consider more possibilities. The gap in the knowledge of resource is a barrier for better AYA care. Therefore the overall picture of the AYA care system should be integrated into the design.
Vooges Centraal, Haarlem, where two interviews took place. Photo by Vooges.
3 AYAs’ Unmet Needs

This chapter discusses the ten unmet needs in sexuality and intimacy care for AYAs. In-depth interviews with AYAs gave the project valuable insights. This chapter lays the foundation for a solution to better communication between AYAs and others, as well as better information supply.
3.1 Unmet needs in sexuality care

Investigations into psychosexual issues have focused on the needs of older adults, resulting in limited information regarding the needs of AYAs. Moreover, unmet psychosexual needs of AYAs may be different from older survivors. Due to the importance of sexuality at this life stage, psychosexual concerns may impede AYA identity formation and health-related quality of life (Dobinson et al., 2016).

Dobinson et al. categorized the unmet psychosexual needs of AYAs into six items based on interviews with eleven AYA cancer survivors: fertility concerns, sexual communication, dealing with side effects, dating and disclosure, relating to other AYAs, and reconciling identity conflict.

The national cross-sectional survey about sexuality and intimacy among AYAs in the Netherlands (Haj Mohammad, 2019) listed AYAs’ satisfaction with received information of eight items concerning sexuality and intimacy care: information for partners, sexual tools, professional help with sexual issues, how to deal with sexual issues, where to find relevant information, which healthcare professional to approach in case questions occur, consequences of treatment on sexuality. AYAs who wrote “did not receive” or “received information but was dissatisfied” counted for more than 50% of all the respondents (N=56) for all the 8 items.

“Fertility concerns” was taken out of the list for this project. Offering options, giving psychoeducation on it and fertility preservation are already parts of the standard care for AYAs in the Netherlands. “On Wednesday, I heard I got cancer, and on Thursday, I was already in the fertility clinic at AMC, then I started hormones [treatment for preservation] on Friday. They had so much knowledge about it. I had an intake of 3 hours about the options etc. They had good, clear information with pictures for me and my partner.” (AYA Emma, 2019). The need to learn to cope with fertility issues falls under other items such as “professional help” and “information for partner”, depending on the specific issue.

Based on the two lists “psychosexual unmet needs” and “items of dissatisfied information supply when there is a need”, the unmet needs in sexuality and intimacy care for AYAs were clustered and rephrased into ten items. The list does not intend to be exclusive on each item or exhaustive in the listing. It is a helpful material to facilitate discussion with AYAs and a guideline for the design.

1) Professional help

Example: “Something about sex bothers me. Who can I talk to about this condition?”

2) Information access

Example: “Where to get the information I need about sexuality and intimacy?”

3) Reconciling identity conflict

Example: “Cancer identified me for so long. Who am I now?”

4) Information for partner

Example: “What’s good for my date/partner to know? Where can we get the information?”

AYA Emma. (2019). Discussing unmet need of AYAs [In person]. The Hague.


5) Referral pathway
Example: “I have an issue with my sexuality and intimacy. How to find the right expert?”

6) Sexual communication
Example: “How to talk about changes and needs in sex with my date/partner?”

7) Dating and disclosure
Example: “Dating feels different now. Should I tell him/her about my cancer? How do I tell?”

8) Dealing with side effects
Example: “Is it side effect? What can I do about it?”

9) Relationship to AYAs
Example: “I want to talk to someone who understands me. How can I get in touch with other AYAs?”

10) Sexual equipment
Example: “Is there a sexual aid that can help me enjoy sex better?”

3.2 Interviews with AYAs

3.2.a Q-sort for different unmet needs

- **Professional help**
  “Something about sex bothers me. **Who can I talk to about this condition?**”

- **Information access**
  “Where to get the information I need about sexuality and intimacy?”

- **Reconciling identity conflict**
  “Cancer identified me for so long. **Who am I now?**”

- **Information for partner**
  “What’s good for my date/partner to know? Where can we get the information?”

- **Referral pathway**
  “I have an issue with my sexuality and intimacy. **How to find the right expert?**”

- **Sexual communication**
  “How to talk about changes and needs in sex with my date/partner?”

- **Dating and disclosure**
  “Dating feels different now. Should I tell him/her about my cancer? **How do I tell?**”

- **Dealing with side effects**
  “Is it side effect? **What can I do about it?**”

- **Relationship to AYAs**
  “I want to talk to someone who understands me. **How can I get in touch with other AYAs?**”

- **Sexual equipment**
  “Is there a sexual aid that can help me enjoy sex better?”

*Figure 13. The cards used in Q-sort with AYAs.*
Five individual interviews with AYAs were conducted from late March to late April in 2019 to discuss the unmet needs and review the initial design ideas. They were reached through the National AYA Young & Cancer Congress 2019. All of them were at rehabilitation or survival phase. The Q-sort methodology was utilized in the “unmet needs” part of the interview. AYA interviewees were asked to place ten cards according to how relevant it was to their experience. There were also blank cards in case they wanted to add something, but all interviewees found the listing complete.

The cards and Q-sort were very effective in opening conversations, especially the more sensitive ones. The burden of saying “sex”, “sexual” and “sexuality” was relieved for the interviewees as these words were read out by the interviewer at the beginning and were put on the table.

While sorting the cards, the AYA interviewees were asked to talk about their experience related to each need or anything that came to their mind when they thought about this need.
The interviewees shared a lot of concerns and experience about each unmet need. They put extra emphasis on “1) professional help”, “2) information access”, “4) information for partner”, “5) referral pathway”, “6) sexual communication” and “8) dealing with side effects”, and less emphasis on “10) sexual equipment”. The rest three unmet needs were also considered important to them.

Therefore, all unmet needs besides “10) sexual equipment” will be addressed in the design.

3.2. b Insights about each unmet need

The AYA interviewees shared a lot of experience and valuable thoughts in the interviews. A compilation of the quotes for each unmet need can be found in appendix B. Here gives a summary of the insights for each unmet need.

1) Professional help

1. a) Primary contact
In the primary contact with healthcare providers, e.g. with an oncologist, gynaecologist, nurse or GP, few people knew how to help when the AYAs had sexual health problems, and they tended to avoid the talk.

1. b) Nurses are important
Nurses had an important role because they connect with AYAs more, but some found it hard to talk about sex.

1. c) Useful short conversation
In many cases, AYAs weren’t looking for intensive therapies. Instead, a short conversation would be already helpful if they could share their concerns and learn some tips. This is also supported by Dr Beekman: “People think when you discuss something, you have to do something with it. But it’s not true. In 75% cases, just listening is enough.” and Senior Nurse Swinkels: “Sometimes it’s enough to just talk about it with someone. Their worries, their thoughts. Because that’s the most important thing.”

1. d) Reliance is essential
Reliance is important when talking about sexual health. As a result, some didn’t ask oncologists or GP, etc., when they had concerns.

1. e) Males need support
In addition, males are less involved in discussions, but they also need support.

2) Information access

2. a) Not what AYAs want
There is a lot of information on the internet, but what the AYAs could find was not what they needed. For example, there was very little practical information or explanation of disturbances. Moreover, they are sometimes too medical, or not always reliable, and not aiming at the individuals’ situation.

2. b) Searching is hard
Searching from the unorganized pool of information was hard and took a lot of energy of the AYAs. Even if they found something, it was not always about the specific situation of AYAs concerning the age and life stage.

2. c) AYAs feel not informed
Sometimes the AYAs felt they were not informed of what was going to happen, and that caused negative feelings.
3) Reconciling identity conflict

3.a) Positive and negative influence
Some AYAs felt lost after the treatment. Some had positive influence from cancer.

3.b) AYAs want to live normal
Despite the burden of cancer, AYAs wanted to live a life as normal as possible.

4) Information for partner

4.a) Partners need attention and support
The partner is also affected by cancer, and they need information and support in coping with the impact. The partner has needs too, but much less attention is given to them.

5) Referral pathway

5.a) AYAs don’t know where to go or whom to find
The AYAs didn’t know where to go to, or whom to find for their problem unless he/she had professional knowledge about the healthcare system.

5.b) First step is a burden
The first step of reaching for help is a burden. To take the action of calling their GP or going to an expert is hard.

5.c) Support should be easy to reach
Because a lot is going on in AYAs’ lives, the healthcare provider should be easy to reach, so AYAs don’t need to put it too much time and effort when they need support.

6) Sexual communication

6.a) Intimacy sees a lot of changes
Intimacy during cancer sees a lot of changes. The energy level, the body image, the body condition, etc., all have an influence on how AYAs experience intimacy.

6.b) Sex is hard to talk about
Sex is an emotional and hard topic to start with. The AYAs need something concrete so they can start somewhere.

6.c) Positive and negative influence
The relationship can be affected by the lack of sexual communication, or become closer because of good sexual communication.

7) Dating and disclosure

7.a) Need a good moment
Disclosing cancer is confronting and makes AYAs feel vulnerable. A good moment is needed where the AYAs feel comfortable and can take time building up to the topic.

7.b) Dating becomes harder
Cancer makes dating harder because of its impact on emotions in short-term and impact on the body in the long-term.

8) Dealing with side effects

8.a) Temporary and long-term side effects
It’s easier to deal with side effects if the AYAs know that it is just temporary. For the long-term changes, it is hard to be completely emotionally prepared.
8.b) Worry is a burden
Cancer brings worries to AYAs, but it is not always necessary. It is a burden.

8.c) Impact starts after treatment
The real impact on sexuality and intimacy starts after the treatment. It is when the cancer is gone, AYAs start coping with the impacts of cancer.

8.d) AYAs need to be reassured
AYAs need to be reassured that seeking help about side effects is not overreacting. Cancer was much harder to fight does not mean sexual health is unimportant.

8.e) Side effect impacts sexuality
Side effect on body image impacts feelings and sexuality.

8.f) Emotional support is important
Besides medical support, emotional support on coping with side effects is also important.

9) Relationship to AYAs

9.a) Learning others’ experience is reassuring
It is reassuring to hear that other AYAs have similar situations. Learning about other AYAs’ experiences makes AYAs feel that they are not alone with their struggles, and that helps them deal with cancer better.

9.b) Special bonds
Moreover, AYAs can form very special bonds and support each other because they have been through similar hardship. They truly understand each other’s struggle.

10) Sexual equipment

10.a) Hard to find and get
It is both hard to find and hard to get the right equipment that helps AYAs deal with sexual problems, such as a lubricant (Because they don’t know whether they can treat it in the same way as menopause. The mechanism is not explained to them. Moreover, they also don’t really know how to deal with menopause at this age).
### 3.3 Summary

In this chapter, the unmet needs of AYAs in sexuality and intimacy care were discussed: professional help, information access, reconciling identity conflict, information for partner, referral pathway, sexual communication, dating and disclosure, dealing with side effects, relationship to AYAs, and sexual equipment.

The interviews with AYAs were effective in gaining insights about the unmet needs in sexuality and intimacy care for AYAs. All the interviews were recorded under the permission of the AYAs and transcribed. Below summarizes the insights.

#### To reassure AYAs

First and foremost, AYAs need to be reassured that seeking help about side effects is not overreacting and that it is not abnormal to have disturbances.

#### About information

There is a need for an information directory that is organized, reliable, easy-to-understand, and tailored for AYAs for better sexuality and intimacy care. Searching from the unorganized pool of information is hard and takes a lot of energy. What AYAs normally find is not what they actually need. Moreover, they are sometimes too medical, or not always reliable, and not aiming at the individuals’ situation or the age range of AYAs.

Basic psychoeducation is important. In most cases, it is already helpful without intensive intervention. In addition, the information should look beyond the disturbance that AYAs face at the moment and prepare them for upcoming changes as much as possible. Information for AYAs at rehabilitation and survival phases should be emphasized because the heavier impact on sexuality and intimacy starts after the treatment when AYAs start to cope with the impacts of cancer.

The side effect is an important topic because cancer brings AYAs many worries. It’s easier to deal with if the AYAs know that the side effect is just temporary, or that it is not abnormal because other AYAs also experience it.

Practical information such as finding the healthcare provider in the neighbourhood, and tips for dealing with sexuality issues are necessary.

#### About communication

With the date/partner, cancer brings many changes to intimacy, but sex is an emotional and hard topic to start with. For AYAs without a relationship, the impact of cancer on emotion and the body makes dating harder and disclosing cancer is confronting. For those with a partner, sexual communication can influence the relationship. The partners of AYAs are also affected by cancer, and they need information and support in coping with the impact, but much less attention is given to them compared to AYAs.

With the healthcare providers, AYAs don’t know where to go to, or whom to find for their problem, and the first step of reaching for help is a burden. Not many healthcare providers in the primary contact of AYAs know how to help when the AYAs had sexual health problems, and some tend to avoid the talk. Nurses have an important role because they connect with AYAs better.

With fellow AYAs, the special connections between them help AYAs feel reassured, understood, supported, and cope with cancer better.
4 Design Decisions

This chapter makes design decisions for the concept design in phase 2 based on the key findings from phase 1.
4.1 Review of research findings

The assignment was to design a patient-centred concept that facilitates the conversation on sexuality and intimacy for AYAs, and to provide them with information at the right time in the right way. The two focuses, communication and information, were discussed in the two chapters above.

Chapter 2, the big picture and chapter 3, AYAs’ unmet needs, looked into AYAs’ communication with healthcare providers, their partners and fellow AYAs, as well as their need for information including when do they need it, what is helpful and how it should be presented.

The complexity of sexuality and intimacy care is worth noting. AYAs have different needs when they have different types of cancer, in different phases in the cancer journey, or have different levels of knowledge about the healthcare system. Moreover, the AYA care resource is not evenly distributed among the Netherlands, leaving some AYAs with much less support.

The gap in the knowledge of resource is a barrier for better AYA care. It hinders the communication on sexuality and intimacy between AYAs and healthcare providers. “Step one” is hard to take if someone does not know whether there can be a “step two”.

In most cases, AYAs do not need intensive intervention. Permission to discuss sexual health and basic psychoeducation are already very helpful. It is, however, not always supported by healthcare providers because of many barriers. To bypass the barriers, patients can try to initiate the discussion.

When it comes to sexual health, it is important that the AYAs feel reassured that seeking help is normal, know that there will always be a healthcare provider who can help and that they are not alone.

An information directory that is organized, reliable, easy-to-understand, and tailored for AYAs, with emphasizes on basic psychoeducation, especially information about side effects, and practical information, is desired by the AYAs.

Café Restaurant Pan, The Hague, where one interview took place. Photo by Café Restaurant Pan
4.2 Design Decisions

4.2.a Core message of the design

The core message of the design is two-fold.

Firstly, it is normal to have disturbances, and seeking for help about sexuality and intimacy is an appropriate action to improve the quality of life.

Secondly, the Dutch healthcare system has a good resource for AYAs in sexuality and intimacy care, and AYAs (and partners) can take an active role in reaching support.

4.2.b Structure and content of the design

“Body map”

A “body map” for information on biological and psychological disturbances. This part focuses on the explanation of disturbances and tips on how to cope with them.

“Directory”

A “directory” for communication between AYAs and healthcare providers, partners and fellow AYAs. This part provides support on how to communicate about psychological and social disturbances. It also includes a part for side effects that are happening and what could happen in the healthcare provider part.

The biological disturbances shown in the “body map” contains the same information as the side effects part of the “directory”, but presents it in a visual way. This is because biological and psychological side effects are an important part of AYAs’ concern, as suggested by the AYA interviewees. AYAs can benefit from basic psychoeducation about the prevention and management of side effects in both visual and text-based manners.

“Love notes”

A “love notes” function for emotional support. AYAs can both receive and write “love notes”. This part helps AYAs see that their concerns are recognizable in other AYAs’ experience, and someone out there truly understands them. AYAs can use heartwarming words to give each other comfort.

Other functions

Other desired functions such as searching for keywords, saving useful information, seeing only resource that are easily accessible from the AYA’s home, etc. are also important to be integrated into the design.

4.2.c Guide for the design

The project chose to develop the design in the form of a website and a mobile application.

Heffernan et al. created three recommendations for developing interactive eHealth apps for complex messaging:

1) Involve a multidisciplinary team

The first recommendation is to Involve a multidisciplinary team in the development process. This project involved sexologists, oncology nurses, AYAs, and doctors and designers from the Dreamteam. The ongoing support for the content of the design should also include this multidisciplinary team.
2) Manage complex messages to engage users.

Complex messages in the context of this project means the care for different individuals concerns individualized and varying messaging (information that the user receive). Therefore some information from the user is necessary, including gender, cancer type, phase in the cancer journey, treatment received, hospital name and city of the user. The type of cancer and the phase determine what is relevant for individuals, which can be very different between AYAs. Tailoring to the users’ situation allows them to receive more accurate information and avoids unnecessary worries. Meanwhile, because the AYA care resource in different places in the Netherlands varies. Showing the user what they can access is more practical.

3) Design for interactivity

Interactivity stands for tailor recommendations, remove barriers to use, design for simplicity, etc.

First, the design is digital. Because the amount of content to be presented to the patient is beyond what a small booklet can present, and the content needs to be updated regularly to be reliable. A digital form can be easier to present and to stay up-to-date.

Moreover, eHealth interventions are recognized to have a tremendous potential to promote patient engagement (Barello et al., 2016). Interactive health communication with the application helps the patient learn about sexual health step by step.

To lower the barriers to use, the design includes both a website and a mobile application. The website provides low-barrier one-time searching function, while the mobile application is the medium for personalized care. The application is able to provide interactive, tailored recommendations, and is also more portable than a laptop, allowing more chance to be used.

The decision of designing both a mobile application and a website is also made upon feedback from AYAs and the Dreamteam. Some AYAs want “a companion” on the phone that is able to offer support whenever they need it, and knows their situation, so that they only see relevant information (e.g. Breast cancer patient will not see information specific to leukemia treatment). Other AYAs do not want to be reminded by an icon on the phone that they have (had cancer). The opinions were two sided and should both be valued. Therefore the design offers two options.
5 Concept Development

This chapter shows the concept development process from initial ideas to prototype iterations. Each step builds upon the reflection of the feedback from the previous step.
5.1 Initial ideas

At this stage, the decision of “preparing the patients for the discussion with healthcare providers by information giving” was already made, which can be seen in chapter 2. The initial ideas explored ways to manage complex information. There were four initial ideas discussed with the two mentors of this project. Below gives a summary of the idea description, feedback and reflection.

**The interactive anatomy map:**

Biological disturbances can be complex and hard to understand. Idea 1 is an interactive anatomy map of sexual organs. The user can zoom in and out to organ-level, tissue-level and cell-level. For each level, it shows the problems that may occur because of cancer and the treatment.

Feedback: This one is also very medical and misses other layers.

Reflection: From understanding the mechanism of treatment to coping with disturbances, there is a long way to go. Explanation of medical things may not easily be transferred to benefit for patients.

**The chemo/radio journey:**

Learning about how the main treatments chemotherapy and radiotherapy work can help patients understand the side effects they experience. Idea 2 asks users to be a molecule of the chemotherapy drug, or a wave of radiation, and travels in the body of a patient and learn about how they affect the body.

**The pet libido:**

The “Balance Method” is a framework used in couple sexual rehabilitation (Reisman & Gianotti, 2017). By investigating the inhibitory and stimulating factors, such as worries, anxieties and physical damage, patients gain insight of their situation. The virtual pet game helps users understand what inhibitory and stimulating factors are and what can they do to improve their situation. The users “feed” their
pet libido by reading a short text and answering questions and get a reward for engagement of the game.

Feedback: An interesting idea of a digital pet, similar to Tamagotchi from the 1990s. What kind of experience does it offer? How to “seduce” users into using it? What is the information provision?

Reflection: The idea is intriguing, but it is hard to keep users engaged for a long time. The information that can be delivered to the user is therefore limited and may not require a game.

The painting of various levels:

AYAs’ need for support is multifaceted. The artistic painting of various levels, has 6 levels from the country (e.g. healthcare system, national organisations), societal level (e.g. acceptance), interpersonal level (e.g. relationship formation) to self level (e.g. body condition), organ level (e.g. pain, numbness) and tissue level (e.g. hair cells generation). Each level is like a page of an interactive encyclopedia.

Feedback: The view is broad. The division of layers is clear. More thoughts need to be put into information provision.

Reflection: It is good to recognise AYAs’ multifaceted need and organise the information in such a way. How should the information be provided? Can the patients easily find what they need? What about AYAs in different situations? Should the painting adapt to individuals?

5.2 Prototype iteration

5.2.a Storyboard

After reflecting on the initial ideas, four storyboards were made to better understand how the design would be introduced to the patient, how to use it, and what patients could get from it.

Figure 20. Storyboard 1: My breast will be removed. What could happen?

Sanne is 22 years old. She was diagnosed with breast cancer last week. Now she is in the decision phase where she is told that she needs to have both breasts removed. She is most concerned about sexuality consequences. Together with her partner, they use the application to learn about the possible consequences and how to manage them. By completing short, fun learning sections, they gain rewards. They feel more informed and prepared for the surgery.

Figure 21. Storyboard 2: We feel drained. How to talk about it?

Johanna is 24 years old. She was diagnosed with lymphoma and has just completed her treatment. She still misses her hair and eyebrow, and she is tired a lot. Both Johanna and her husband feel drained after cancer,
and she feels that they are not intimate anymore. She searches online “how does cancer affect sex life?” and finds the application. She gets practical tips on how to talk about her situation and feels reassured that it is an important matter. They have a heart-to-heart conversation.

Mark is 32 years old. He is a testicular cancer survivor. He has a happy, loving family with two children and a good relationship with his wife. But five years after he was cancer-free, he still feels insecure and anxious about sex. His wife Maria mentions this to her therapist and knows about the application. The application gives her explanation of why things happen, and she now understands her husband better. It also suggests her to see a sexologist with her husband.

Dennis is 30 years old. He was shocked when he found that he had a recurrence of colon cancer, and it was terminal. He decided to go for palliative care. He wants to make the best of what they have with his wife. They find the application where they learn about the meaning of intimacy again - it is about love, connection and feelings. They learn to enjoy intimacy without being sexually active, which brings both of them great comfort.

\[5.2.b\] Prototype version 1

![Figure 22. Storyboard 3: He still feels insecure. How can we solve it together?](image)

![Figure 23. Storyboard 4: It won’t get better. We want to make the best out of the last days.](image)

![Figure 24. Prototype version 1.](image)
The application has six levels: societal, family, partner, self, body, organ. The user can zoom in to different body parts/body functions to gain information, e.g. “Brain” for the effect of chemotherapy on memory and thinking ability.

For each level, “knowledge bubbles” pop up randomly. Through gaining information about each body part, like reading a short text and doing multiple choices, the user gains “badges” as a reward. It motivates the AYA to learn more. The design style hopes to make the topic of sexual health light-hearted.

Feedback and reflection

This prototype was shown to three AYA interviewees. The feedback and reflection include:

Reassurance: [I want to be told] “You’re not the only one. You’re not weird for having this problem.” (AYA Emma)

Practical information: Where can I find this expert? I need guideline for reaching certain help, clear, easy, written down on a page. General hospitals miss this information, but it is important (AYA Emma). Tips for the partner on how to start this conversation (AYA Daan).

Inform: What does that mean to me and my body? (AYA Emma). I didn’t get all the information I should get (AYA Lisa).

Literacy and education levels: Symbols and language need to be easy to understand because not everyone has a bachelor’s degree (AYA Lisa). Some information is even too medical for people with higher education.

Also for the partner: I’d like for my partner to use it too. It is not a lot of effort to look on it (AYA Emma). If the partner says “Hey, have you been working on it?” it motivates them (AYA Daan).

Make it more gender-neutral: It looks girly, which works if you want the girl to push the guy AYA to use it (AYA Daan).

Consider different coping styles: Men put their sorrow away or hide it. Women have a more approaching form of coping. Also, everyone deals with it differently (AYA Daan).

The prototype was also discussed during the mid-term meeting. Information provision was an important point for further development.

Information provision: The provision of information to patients is one of the most important factors of supportive cancer care across the whole cancer continuum. From the perspective of the patient, information provision is mostly measured in terms of “satisfaction with received information”, “barriers to receive information”, “information needs”, “information quality” and “information clarity” (Husson, Mols & van de Poll-Franse, 2010).

The way for AYAs to get the right information about a specific topic should change from “exploring” to “being directed”. The type and amount of information the patient might need varies per person. If the application is the same “interactive encyclopedia” for everyone which shows everything available, it takes time for the user to find what he/she needs. But as suggested by the AYA interviewees, “you don’t have all the energy to look for information (AYA Emma)”. If the users are directed in a structured way, they can find the right information with much less effort.

It should be easy for AYAs with different needs to find what they want. For “information quality” and “information clarity”, different AYAs have different expectations for the information. Some want medical explanations of why certain things change, some want simple, supportive, one-line quotes, and others want personal stories that they can relate to. Information that one AYA finds high-quality and clear may appear complicated to another. Medical information and supportive information should both be accessible in the application with a clear division.

AYA Daan. (2019). Discussing unmet need of AYAs [In person]. Utrecht.
AYA Emma. (2019). Discussing unmet need of AYAs [In person]. The Hague.
AYA Lisa. (2019). Discussing unmet need of AYAs [In person]. Arnhem.
Part 1: Setting up

The application asks for some basic information of the user, including gender, phase of the cancer journey, the type of cancer and the type(s) of treatment. This information is used to personalise the content of the application, e.g. the side effects of treatment and how to manage them. The user can always change this information later.

Part 2: Body map and directory

The “body map” on the left page has three functions: “question” (drag to a body part), “learning” (randomly pops up somewhere) and “love notes” (both receive and send). The “directory” on the right page is about how to talk to someone, including doctors, AYAs’ partner, and fellow AYAs. The information architecture should be organised and structured.

Part 3: Sidebar

In the sidebar, the user is able to see their browsing history of every part of the application and save what they find useful.

For the design decisions, please refer to “4.2.b Structure and content of the design”.

Figure 25. Prototype version 2.
Feedback and reflection

This prototype was shown to three AYA interviewees and the mentors of this graduation project. The feedback and reflection include:

Use of icons: Very nice that the icons are ethnically and religiously diverse. This way, more people will feel comfortable using this application (AYA Lisa). The icons for “survivor” (strong arm) and “palliative” (leaf) look like patients who enter the palliative care phase is less strong. But that is not the case. In addition, the icons for “question”, “learning” and “love notes” are not easily understandable, probably because the functions are new in the first place.

Lighthearted “vibe” of the application: To talk about those intimate things you really want to trust someone, almost having fun with someone (AYA Leon). So the “vibe” of the application should be lighthearted. When choosing colour and shapes, as well as the language, attention should be paid.

Practical information: If I know it is just next door, then I’ll give it a shot. For a lot of people in their 20s who have this, just not talking about it (“making a big deal out of it”) for once is very helpful as well (AYA Leon). So users should see people and resource that they can easily approach.

Personal stories: [Hearing other AYAs’ stories at an outdoor activity] made me feel happy and thankful for my situation. It was very positive (AYA Anne). There are many organisations and websites that have a compilation of stories from cancer patients, e.g. Rutgers Foundation, Vereeuwigd Initiative, Teenage Cancer Trust (UK). They can be a source of the personal stories (with the consent of the author).

Privacy: It is a sensitive topic. Either there is a way that the user feels safe, or the user is totally anonymous, like browsing a simple website, but then it is hard to personalise the content every time.

5.2.d Prototype version 3

Part 1: Name, logo and the registration

The name “New Me. New We.” is inspired by the Dutch sexologist Woet Gianotten’s ideas of “the new me” and “the new we” (Reisman & Gianotten, 2017) for patients when they rethink sexuality and intimacy under chronic conditions. The logo represents a superherp couple

AYA Anne. (2019). Discussing unmet need of AYAs [In person]. Delft.
AYA Leon. (2019). Reviewing the design prototype of New Me. New We. [In person]. Haarlem.
AYA Lisa. (2019). Reviewing the design prototype of New Me. New We. [In person]. Arnhem.
sharing the same cape. The feedback on the name and logo was very positive. AYA Lisa said “I really like the quote ‘new me, new we’. It is new, it is forever different, you’re never going to be the same person again. Even if you’re in a relationship, it’s different. You have to look for a new normal, to find a way to deal with all the changes.”

The registration part says “New Me. New We. is a safe data island. Your account cannot be traced from your social media account, email address, phone number, etc. You may choose to share part of your data with your healthcare provider by exporting a report.” and “Always consult with your healthcare provider.” The user registers with a unique username and a password. His/her username is the only identifiable information. The user is then given a code as the encrypted key to retrieve the account in case he/she forgets the username or password.

Part 2: Basic information

This part asks for the basic information of the AYA (and partner, because at this stage the design tried to include partners as the user), similar to prototype version 2. The icon design was reviewed with some AYAs. The “type of cancer” part is different for males and females. Some use of words were discussed, e.g. rehabilitation or recovery, palliative or soothing. At this stage the design keeps the medical term. Before introduced to real users, the language should be reviewed by experts from institutions like Stichting Lezen & Schrijven (Reading & Writing Foundation).

Part 3: Body map and directory

The next page shows the two main pages of the application. The body map on the left page is about biological disturbances (“question” and “knowledge”) and emotional support (“receive love note” and “send love note”). The directory on the right page has a information architecture shown in figure 29. The information architecture was reviewed and revised with two sexologists.
Figure 28. Prototype version 3, body map and directory part.
Beekman, A. (2019). Reviewing the structure and content of New Me. New We. [In person]. Leiden.
Gianotten, W. (2019). Specific interventions for AYAs and reviewing the structure and content of New Me. New We. [In person]. Hilversum.

Figure 29. Information architecture of the directory.
Part 4: The sidebar

Figure 28. Prototype version 3, body map and directory part.

From the sidebar, the user can search for keywords. This is complementary to the two main pages. For example, if the user has a very specific question in mind about various body parts, like numbness of the skin, he/she may prefer to search for explanation about “numbness” instead of dragging the “question” bubble to a certain body part, or looking for the word in the list of common side effects.

The user can also check the bookmarks of their “question” and “knowledge”, the “lovenotes” they saved, and things he/she finds useful from the “talk to...” Directory.

In the setting part, the user can edit their basic information, such as changing the phase of cancer from “treatment” to “rehabilitation”. He/she can also see how many days he/she has been using the application, link to the partner’s account to check on each other, and state which hospital is providing care, so that the content can be further personalised, only showing experts and resource the user can easily reach.

Feedback and reflection

This prototype was reviewed with the supervisory team, the Dreamteam, senior nurse Eefje Swinkels and several Design for Interaction students from the Industrial Design Engineering faculty. The feedback and reflection include:

Patient diversity: Besides the male-female partner “body map”, there should also be drawings of homosexual partners if the user indicates so, drawing of younger bodies since the AYAs can be relatively young and a less mature body image suits their situation better. The user could also be single or have multiple partners, but in these cases, the biological disturbances can still be presented on a male-female “body map”. If the user is bisexual, he/she should see both heterosexual and homosexual drawings. For transgender people, there should be another drawing adapted to their situation. For asexual people, perhaps the content needs further revision.
User Scenarios: Firstly, what is also useful is that the AYAs can use this application as a tool to have discussions with their healthcare providers. They can ask questions while pointing at certain content on the phone. Secondly, some AYAs would like to use it together with their partner with the same screen. The process of getting information together can also bring the relationship closer.

The educational level of the hidden population: All the AYA interviewees were highly educated. Two of them were even medical master students. However, it does not represent the real AYA group. The design was seen as intuitive and well-structured by the interviewees. But others, the “hidden population” of this project, could have difficulty understanding the function of each part and the interaction. This is a common problem in projects like this - the design is not tested by users with a medium and lower educational level. To really benefit all the AYAs, the design should be shown to a more diverse group before being introduced to real users. A language expert should also be involved like suggested previously.

Language: It is important that “what you say” and “what the user understands” are the same. To ensure this, the content needs to be reviewed with healthcare providers who have a lot of contact with patients. Some users can also be involved to test the effectiveness of the messages.

Accessibility features: For (partially) visually impaired users, “larger text” and “read for user” are necessary. It also shows that the application does its best to include as many AYAs as possible.

Differences across the Netherlands: Nurses and doctors from the north and the south have cultural differences. This might influence the patient-healthcare provider interaction as well. Some attention needs to be paid on the differences across the Netherlands before the application is introduced to real users.

User behaviour: How much in-depth does one user want to know? Some may look for detailed academic-style explanations, while others want simple, one-line fact statements. How to meet the needs of different users? Does the application learn user behaviour and adapt?

Form an expert team: To complete the content of the design, there needs to be an expert team. The information they give is reliable, easily understandable and up-to-date. There are already some experts who would like to get involved. How to get them to work together? Will there be a platform for them to log into and provide input?

Vote for updates: The current resource that healthcare providers have does not cover all the questions that AYAs have. Sometimes, doctors also do not know what questions AYAs have. If a lot of users search for the same question (keyword), and there is no answer for that, the healthcare providers should be notified. If the application can show a list of unsolved questions, and ask the users to evaluate which ones they find relevant, healthcare providers can look into them. It creates a good opportunity to improve AYA care.

Website or mobile application: The design is a mobile application. On the one hand, if it is on a website instead of an application, the barrier maybe more people will use it. On the other hand, some AYAs may not want to be reminded all the time by the app icon on their phone that they have (had) cancer. However, the advantage of an application is that the content can be personalised for each individual, which is an important feature. How to balance between the two sides?

Interaction design: Since some functions in the design are new to users. There should be a tutorial when the application is first used. Some icons are not easy to understand. The visual is a bit “busy” that the users don’t know where to look at. The use of serif on shapes and shades make the design look old. Perhaps flat design is better.

Socialise within the application: Some users may want to connect with other users within this app. However, according to the AYA interviewees, deep interaction is not necessary. They only want to feel that there are others out there in the same situation, but connecting with them is too much. Besides, AYA4net has an online community for AYAs to share their experience and connect.
6 Final Design

This chapter first showcases the final design, including the mobile application design and website design. Then it discusses the design implementation plan.
6.1 The mobile application

Based on the feedback and reflection discussed in the previous chapter, the final design was made. Some suggestions were not put into the final design. Instead, they are discussed in the conclusion chapter as future steps.

The main revisions include using the website and the mobile application together, changing the visual style, adding accessibility features, adding “vote for update” function, emphasizing “love notes” function to provide more assurance and emotional support, and showing a map of available resource according to the postcode of the user.

The sample content in the final design was based on the interviews, the book *Cancer, Intimacy and Sexuality - A Practical Approach* (Reisman & Gianotten, 2017), the information from the Breast Cancer Care Foundation (“Breast Cancer Care”, 2019) and the website of the Nederlandse Wetenschappelijke Vereniging voor Seksuologie (The Dutch Scientific Association for Sexology). The love notes were written based on the AYA interviewees’ experience and the personal stories from the Vereeuwigd Initiative (“Vereeuwigd”, 2019).

An animation of the prototype can be found at: vimeo.com/ruocha

In part 1, name, logo and the registration, and part 2, basic information, only a few changes were made. “Partner’s gender” was rephrased into “(Future) partner/date’s gender” to include AYAs who are single and who are not looking for partners.

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**Figure 29. Final logo design.**

**Figure 30. Body part division on the body map.**


Part 3: Body map

“Question”: If the user has a specific question about a body part, he/she can drag the button “question” to the body part. The division of body parts is shown in figure 30. Depending on where the “question bubble” lands, the application will give a list of common problems. Each problem is linked to a short article.

“Knowledge”: Sometimes the user does not have a specific question, but would like to learn more about why something happens or what could happen, so they can have better control of their situation, or prepare for what is ahead. The “knowledge bubble” will randomly pop up on a body part in relation to the AYA’s situation, e.g. If the AYA receives chemotherapy, it is possible that “hair loss” is shown to him/her.

The “question” and “knowledge” functions share the same database.

“Love note” and “send note”: There will be a compilation of heartwarming “love notes” from AYAs that the users can receive. This gives AYAs emotional support, which was suggested by the AYAs in the interviews. The compilation starts with quotes from existing AYA stories (with the consent of the author). With more AYAs using the application, some may want to write love notes for others. As suggested by some interviewees, simple words from someone who is going through the same thing can be very powerful. For example, “you are not less of a woman without a breast”. But it has to be from another AYA. Therefore the application shows some basic information of the one who writes the note, including name and cancer phase.
Part 4: Directory

The “directory” is to support communication between AYAs and healthcare providers, partners and fellow AYAs. The most crucial underlying insight is that in many cases, intensive intervention is not needed. Instead, providing relevant information to the AYAs is already helpful. Although it shows “talk to...” on the screen, it only means the AYAs have the need to talk about it, and their concern can be solved by getting information instead of actually talking to a healthcare provider.

Information available to AYAs about sexual disturbances is no specific to their situation, sometimes too medical or not reliable, etc. The “directory” gathers reliable, relevant information and present it in a structured way. The information architecture of the directory can be seen in figure 29.

Figure 31. Directory part of the mobile application design.
Scenario 1, when a female AYA experiences vagina dryness and does not know why it happens or how to manage it.

As can be seen from the wireframe, here showcase three sub-functions: expanding the information tree, react to an article, prepare to talk to someone.

Expanding the information tree: Although the amount of information is big, the design tries to show it in a succinct way.

React to an article: The user can evaluate whether the article is helpful, copy it, bookmark it, and add it to the “talk to” list.

Preparing to talk to someone: Taking the first step to reach help is a burden, as suggested by the AYA interviewees. “Seeing your GP, doctor or nurse” may sound easy, but to act on it is different. Therefore the application first gives practical tips such as “You can be straightforward and bring up a concrete question, like ‘After the treatment, my vagina dryness caused discomfort. Do you know what kind of moisturisers I can use?’”. In case the healthcare provider at the general hospital is not able to give an answer, the AYAs should know that the AYA team in the UMC can also help by reading “You can also ask your doctor or nurse to refer you back to the UMC, where there is an AYA team that offers complex care too.”

Figure 32. Directory part of the mobile application design, scenario 1.
Scenario 2, when an AYA has an altered body image and wants to learn how to get along with the new body.

Here shows another sub-function: finding specialists or resource in the neighbourhood.

**Finding specialists or resource in the neighbourhood:** As suggested by the AYA interviewees, young people have a lot to do in their lives. It is not practical for them to travel very far for support. Putting too much effort in reaching for support also makes them feel “they are making too big of a deal out of it”. Therefore, it is useful to provide information about specialist and resource in the AYAs’ neighbourhood. By seeing it, the user may realise “It is not that hard, so I want to give it a shot.” They will also see the contact information of the specialist and resource, so if they have doubt about reaching for support, there is a lower barrier for them to take the first step: make a call with the number shown on the phone.
Compared to the prototype, the sidebar added a “help us improve” (vote for update) function, where the user gives the opinion about whether a concern is relevant. In the “searching” part, the user can also list the question in case it does not have an answer yet. These two functions enable the application to learn about the unmet needs of AYAs continuously and to keep improving the content.

The “bookmarks”, “love notes” and “talk to...” parts list the items that the user has saved. In the “talk to...” part, the user can also “check” the items that he/she already acted upon.

In the setting part, it is possible to change the basic information and to have an overview of the resource in the neighbourhood.
6.2 The website

**New Me. New We.**

Sexual health is never unimportant.

Having cancer around your twenties is really something different. Concerns about sex and relationships are very normal, yet information is hard to find. You are not alone on this. Here is the information toolkit designed with AYAs, for AYAs*.

AYA: Adolescents and Young Adults (AYA) with cancer, diagnosed at 15-39 years old

What's on your mind?

*Figure 35. Main page of the website design, part 1.*
The main page of the website is scrollable. It has two functions: to provide low-barrier one-time searching function, and to give the first level of sexual health intervention: Permission.

**Providing low-barrier one-time searching function:** The function is straightforward and clear, showing to the user “Yes, you have found the right place to search for whatever you want to ask”.

**Giving the first level of sexual health intervention:** As discussed in chapter 3, the most important idea of the design is that AYAs need to be reassured that seeking help about side effects is not overreacting and that it is not abnormal to have disturbances. Furthermore, they can take an active role in promoting their own quality of life.

The two enlarged lines “Sexual health is never unimportant” and “You can take an active role” convey the core message. The smaller texts were also written according to the PLISSIT sexual health intervention model: “Having cancer around your twenties is really something different. Concerns about sex and relationships are very normal, yet information is hard to find. You are not alone on this. Here is the information toolkit designed with AYAs, for AYAs.” And “Your feelings and concerns are real in this new situation. How to adapt? How to create? New Me, New We. supports you with the right, age-specific information and resources.”

Listing the common disturbances in the middle of the page reassures the user that they are not strange for having a problem. In fact, their concern might be one of the most common concerns among AYAs.

At the end of the main page, the website promotes the mobile application by explaining the advantages: “Everyone has something different. Big amount of information can be overwhelming. With the app, only information tailored to your situation is presented.”
Good afternoon Eefje!

Thank you for your input!
Here is an overview of the reactions to your 63 articles from the past week.

- **567 view counts**
- **98% found useful**
- **123 bookmarks**
- **17 acted upon suggestion**

4 questions in your field are not answered yet.

- 75% find relevant: I'm scared of sex after breast cancer, what can I do? [Link]
- 40% find relevant: My partner becomes distant after my diagnosis. What can we do? [Link]
- 90% find relevant: How sure it is that I can become pregnant with IVF using the eggs I preserved? [Link]
- 80% find relevant: A lot is going on right now. How will my relationship be affected? [Link]

3 articles need your help to review.

- How does a male breast cancer diagnosis affect the relationship? [Link]
- Why do I feel an increase in libido on Tamoxifen? [Link]
Figure 37 shows the healthcare provider portal for the expert team that fills the content for the application. It first gives an overview of the healthcare provider’s contribution and impact. Then it lists the questions the healthcare provider is asked to write about. They are questions that users submit from the mobile application. It also shows how relevant it is according to AYAs’ opinions from the “help us improve” part. This information helps the healthcare provider see which concern is more important.

### 6.3 Design implementation

Firstly, to ensure that the information provided is accurate, reliable and easily understandable, each article is reviewed by fellow healthcare providers and language experts. As mentioned in the previous chapter, it is important that what is written is what the user understands. The way to ensure that is to let healthcare providers who have a lot of contact with patients review the text, e.g. oncology nurse and sexologist. In addition, the language experts can make necessary changes to the words so that the majority of the population is able to comprehend the article well. Below shows how the feedback and information flow.

Secondly, there needs to be an expert team composed of oncologists, urologists, gynaecologists, sexologists with a physician background and with a psychology background, oncology nurses, the director of AYA4net.nl and perhaps director of other organisations that have good knowledge of online and offline support for AYAs. The task division is shown in figure 39. There is already some progress in teaming up the experts.

Thirdly, to realise the design, developers for both front-end and back-end need to be involved. There is some progress made in composing the development team. With this next step in mind, the prototype was built with Framer, making the transition from design to development and the future collaboration between the designer and the developers easier.

Lastly, because of the limited funding, the first version of the application will not look the same as the final design shown in this report. Complex interaction like dragging “bubbles” and advanced functions of showing an interactive map within the app and gaining user feedback can be put on hold. The main focus of the first version would be to gather and present information in a structured, easily understandable way. If the project can attract more funding, small steps toward the full version can be taken one at a time.
Figure 39. Expert team members and task division.
This chapter gives general conclusions of the research and design process and discussion for further development.
7.1 Conclusion

The assignment was to design a patient-centred concept that facilitates the conversation on sexuality and intimacy for AYAs, and to provide them with information at the right time in the right way.

The project first conducted a literature study and interview to understand the big picture of sexuality and intimacy care for AYAs in the Netherlands, as well as AYAs' ten unmet needs. Several design decisions were made based on the insights from the research phase.

In the design phase, the project followed the classical iterative design methodology with the human-centred design approach. AYAs were kept at the heart of the design process. The prototype iteration also involved other stakeholders, including sexologists and oncology nurses.

Regarding communication, there is insufficient discussion between AYAs and healthcare providers. The design gives information about the disturbances so that in most cases, the AYAs will have their concerns solved, and prepares them to initiate the discussion with their healthcare providers.

Regarding information, AYAs are dissatisfied with the information supplied. The project looked into AYAs' unmet needs and constructed an information architecture that covers their needs.

After several prototype iterations, the final design shows a mobile application for personalised care and a website for low-barrier one-time search. A portal for healthcare experts to provide input for the application is integrated into the website design. An animation of the prototype can be found at: vimeo.com/ruocha The design implementation plan was discussed.

7.2 Next steps

The prototype received a lot of positive comments from AYAs and healthcare providers. The final design is the result of many design decisions taken throughout discussions with these stakeholders. It has been confirmed by the Dreamteam that the project will be carried on, and there is some funding for the realisation of this design.

From the interviews, it is clear that the design does fill a gap in the current AYA care. The advantage of the Dutch healthcare system is that there are attention and resource for AYA care in sexual health. To improve AYAs' quality of life, there simply needs to be a “bridge”.

To carry the project forward, the expert team that provides the content is the key part. The next step is to team up experts from different fields and enable them to work together efficiently and smoothly.

To attract more fundings and support, the project needs exposure in the future, such as at design exhibitions and the National AYA Congress. It is rather costly to outsource the project to web develop agencies and it is not realistic for this non-profiting project. Therefore the author of this report will keep working on it.

AYAs' partners receive less attention than AYAs, but they also have many needs. To provide a complete AYA care, their needs cannot be overlooked. However, within the project, it was not possible to get in touch with any AYA' partner. This part of AYA care should be integrated before the application is introduced to patients.

If the final design can be realised, there are still some further possibilities for better AYA care. By looking at the user behaviour, the system can learn some things about the user and optimise the content: What is the user’s preference for information provision? What is the coping style (approaching or avoiding) of the user? Is the user showing any sign of depression or anxiety? Etc. Then the application can provide targeted advice for the user.
References

The references include 29 literature, 9 websites and 15 interviews.


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Appendices

Appendix A looks into AYAs’ contact with healthcare providers. Appendix B lists the important quotes from interviews with AYAs.
Appendix A AYAs’ contact with healthcare providers

Because not all healthcare providers were covered in the interviews, a questionnaire was designed to complete the information. The goal of the questionnaire was to identify which healthcare providers are more important/relevant when AYAs want to discuss about sexual health. The result was a reference for mapping out the referral pathway (figure 12) designing touchpoints. The table version of different healthcare providers involved in different phases (figure 11) was sent to the five AYA interviewees together with the questionnaire. AYAs were asked about how much contact they had with each healthcare provider, and how likely they would discuss sexuality with them. Three out of five AYAs responded.

<table>
<thead>
<tr>
<th>Healthcare Provider</th>
<th>In your past journey, how much contact did you have with them?</th>
<th>Hypothetically, if you could have contact with all of them, how likely would you discuss sexuality concerns with them?</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what kind of settings?</td>
<td>n.a. - not applicable</td>
<td>n.a. - not applicable</td>
</tr>
<tr>
<td>Please highlight, e.g. face-to-face/online; private/in group; with partner/without</td>
<td></td>
<td>example of sexuality and intimacy concerns:</td>
</tr>
<tr>
<td></td>
<td>0 - not contact, 1 - limited contact, 2 - some contact, 3 - a lot of contact</td>
<td>0 - not at all, 1 - simple questions, 2 - basic discussion, 3 - in-depth discussion</td>
</tr>
<tr>
<td></td>
<td>notes, if any</td>
<td>notes, if any</td>
</tr>
<tr>
<td>A) GP/huisarts</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>B) Oncologist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>C) Pathologist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>D) Geneticist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>E) Radiography Technician</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>F) Gynaecologist/Urologist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>G) Fertility Specialist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>H) Surgeon</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>I) Radiologist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>J) Hair Loss Adviser</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>K) Oncology Nurse</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>L) Reconstruction Surgeon</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>M) Routine Check-up Specialist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>N) Sexologist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>O) Psychologist/Therapist</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>P) Physiotherapist/Personal Trainer</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>Q) Online Support</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
<tr>
<td>R) Offline Support</td>
<td>face-to-face/online; in private/in group; with partner/without</td>
<td>notes, if any</td>
</tr>
</tbody>
</table>

AYA: Adolescent Young Adult

example of sexuality and intimacy concerns:
- “Is vagina dryness a side effect of chemo? What can I do about it?”
- “I got so emotional in the relationship. How should I deal with it?”
- “Cancer changed my body, I don’t feel masculine anymore.”
- “How to tell my partner that I still want intimacy although I’m too tired for sex?”
- “Is there a sexual aid that can help me enjoy sex better?”
- “How should I tell my date about my cancer in the past?”

ADD examples if possible
Besides the questionnaire responses, the comments from the five AYAs in the interview about their experience was also considered. Because of the small sample size, it was not possible to draw quantitative conclusions. But it provided many qualitative insights.

<table>
<thead>
<tr>
<th>A) GP/huisarts</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Don’t see GP much. No “click”.</td>
<td>Face to face, without partner.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B) Oncologist</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Brief talks. No “click”. Takes care of the medical part.</td>
<td>Face to face, with partner.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C) Pathologist</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Not the one to talk about this.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D) Geneticist</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Not the one to talk about this.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E) Radiography Technician</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Not the one to talk about this.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>F) Gynaecologist/Urologist</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Takes care of the medical part.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G) Fertility Specialist</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Talked about reproduction, fertility, future plans, IVF, etc.</td>
<td>Face to face, both with and without partner.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>H) Surgeon</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Talked about surgery choice and consequence on sexuality.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I) Radiologist</th>
<th>Contact</th>
<th>Willingness</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>Not the one to talk about this.</td>
</tr>
<tr>
<td></td>
<td>Contact</td>
<td>Willingness</td>
<td>Comment</td>
</tr>
<tr>
<td>---</td>
<td>---------</td>
<td>-------------</td>
<td>---------</td>
</tr>
<tr>
<td>J) Hair Loss Adviser</td>
<td>●</td>
<td>●</td>
<td>Not the one to talk about this.</td>
</tr>
<tr>
<td>K) Oncology Nurse</td>
<td>●</td>
<td>●</td>
<td>Could ask simple questions about sex. Nurse was a bit awkward.</td>
</tr>
<tr>
<td>L) Reconstruction Surgeon</td>
<td>●</td>
<td>●</td>
<td>Appointments with surgeons were short, and there was a lot to discuss besides sexuality.</td>
</tr>
<tr>
<td>M) Routine Check-up Specialist</td>
<td>●</td>
<td>●</td>
<td>We had nice connection. We could talk about different parts of life, including sexuality and intimacy.</td>
</tr>
<tr>
<td>N) Sexologist</td>
<td>●</td>
<td>●</td>
<td>I wish I had seen one and talked about the problems I had.</td>
</tr>
<tr>
<td>O) Psychologist/Therapist</td>
<td>●</td>
<td>●</td>
<td>The one I can talk about anything with. But I still felt like I shouldn’t bother talking about sexuality problems.</td>
</tr>
<tr>
<td>P) Physiotherapist/Personal Trainer</td>
<td>●</td>
<td>●</td>
<td>Not the one to talk about this.</td>
</tr>
<tr>
<td>Q) Online Support</td>
<td>●</td>
<td>●</td>
<td>A community of only AYAs made me feel safe to talk about it.</td>
</tr>
<tr>
<td>R) Offline Support</td>
<td>●</td>
<td>●</td>
<td>The gatherings, all the sharing, meant a lot to me.</td>
</tr>
</tbody>
</table>
Appendix B Quotes from interviews with AYAs

I. Professional Help

i. No one knew how to help

I went to oncologist, gynaecologist, nurse, GP. They didn’t know. No one knew (alternative contraception method). (AYA Lisa)

ii. Talk was avoided by healthcare provider

[My own oncology nurse] said “No no, I really don’t know what to say. I’m in great shock actually that you’re so open about this. But still I can’t help you.” (AYA Lisa)

He (the oncologist) just gave me a call and told me to freeze my semen in 3 days before chemo, which was the worst thing you can do. I can never imagine calling somebody and putting this major news, this burden, on him. (AYA Daan)

iii. Nurses had an important role. They connect with AYAs more, but some found it hard to talk about sex

The nurses are the ones you talk to and provides care. (AYA Lisa)

With the nurse we talked about the things I didn’t want to talk to my doctor about. That’s very useful. It’s a different level of connection. (AYA Leon)

In reality when I talked about sexuality with my nurse, she was shocked. She found it hard to talk with me about it. (AYA Anne)

I got a little bit information from the nurses but not very specific. They say this is treatable, you can go to someone with these questions. (AYA Leon)

Nurse really missed a lot of information about hair. (AYA Emma)

iv. Just a short conversation is enough

Maybe just 2 or 3 conversations, some tips, maybe that’s enough. (AYA Lisa)

I didn’t have to do it on my own. Like it’s an open door. But I had to hear it from someone else (that I can open up). (AYA Anne)

v. Reliance is important when talking about sex

I would ask anyone. I’m not shy, but you have to have a click. (AYA Lisa)

I had a good connection with my GP but to talk about sexual matters would be a bit strange for me. (AYA Emma)

My doctor (oncologist) had one main goal and that is to make me clean again and she helped me with that. But that’s not the person I trust if we’re talking about sexuality. (AYA Leon)

The doctor is there to do the treatment. He’s gonna make me better, but I didn’t ask him anything about it (sexuality). (AYA Lisa)

To talk about those intimate things, you really want to trust someone first. (AYA Leon)

I have conversations with my psychologist, but we never really talked about this subject (although I do face a problem). (AYA Emma)

vi. Males are less involved in discussions, but also need support

Woman are more involved in discussions, especially sexuality, but it’s also important for man to talk about it. (AYA Daan)
II. Information Access

i. Information I found was not what I needed

AYA forum lacks practical information too. (AYA Emma)

I googled a lot “how does cancer influence your sexual feelings” then you get a lot of “low energy levels” “you can’t do it”, but it’s not what I’m looking for. I’m looking for how to deal with it now (after treatment). (AYA Emma)

Is it just temporarily? Can we test that? I really want to have explanation for things. Then I can deal with that, or I try to solve it, I just need to know what’s causing it. (AYA Lisa)

ii. Information from internet was sometimes too medical, or not always reliable, and not aiming at the individuals’s situation

If you’re not academically educated, it’s difficult to find the right information, and to know which information is reliable or not. Not every patient has a bachelor’s degree. (AYA Lisa)

So many points of views on google. It’s difficult to see what’s actually true. They might even scare you. (AYA Daan)

My boyfriend has looked on the internet a lot to see what’s happening in my body... he was also scared by the information on the internet. (AYA Anne)

Internet is not really reliable, and everyone is different. (AYA Lisa)

iii. I was not informed of what was going to happen

You don’t feel anything. I never thought about that. This is numb, forever. I feel I didn’t get the information about that. They should have told me. They think “of course you know that” but no I don’t. You should say that, no feelings at all. It also affects your sex life. They never told me about that. (AYA Lisa)

I feel I didn’t get all the information I should get. (AYA Lisa)

During my treatment, I said some “Oh, you could’ve told me earlier...” (AYA Emma)

iv. Searching from the unorganized pool of information was hard and took a lot of energy

You don’t have all the energy to look for information. (AYA Emma)

I had to look up everything by myself. No one knew. That was difficult. (AYA Lisa)

Patients are under such stress. There’s so much going on in your mind. It’s very difficult to organize. (AYA Lisa)

I never know where you can find the proper information. (AYA Daan)

v. Information available was not for AYAs

They [specialized barber] gave me a wig booklet, but it was for older people. Younger people need specific information. (AYA Emma)

Most patients with breast cancer are older with different problems. (AYA Anne)

III. Reconciling Identity Conflict

i. I felt lost after the treatment

I heard people say this (identity conflict) after their treatment and I thought “get over it, it will be fine”. But now I have that as well. (AYA Emma)

I said “I don’t really know who I am” to my mom last week. (AYA Emma)

ii. I want to be the normal self

I didn’t want a hat, just wanted to be as normal as I can be. (AYA Lisa)
I used to be the guy with cancer, and here (after moving to a new city) I don’t need to be that anymore, I want to be Daan, fresh start. (AYA Daan)

iii. Cancer had positive influence on me

Cancer had positive influence on me. I’m really insanely positive. I know people don’t understand where it’s coming from if they don’t know where I come from. (AYA Daan)

IV. Information for Partner

i. Partners are also affected by the cancer and they need information

In Holland we all say “Kanker heb je niet alleen (you have cancer together, not alone).” (AYA Lisa)

How the body can change, how hormonal change affect things, and how much it affects you both. (AYA Lisa)

It’s easy to be the one with the disease. I knew what I felt, what I needed and when I wanted to talk about it, then I’m gonna start to talk about it. I know what feels right for me. (AYA Daan)

… But I would never know what to do in his place (father, or someone else in general). (AYA Daan)

ii. Partners have needs too but much less attention is given to them

He always said “It wasn’t about me. It’s about you. You need care, not me.” (AYA Lisa)

In the hospital they asked how he felt, do you need anything, can we refer you to anyone, but he said “It’s fine, I don’t need that.” (AYA Lisa)

Society has the point of view that you should care for the person who has cancer. (AYA Daan)

The attention is mostly toward the patient. If they (the partners) say “I’m fine”, what are you gonna do? (AYA Lisa)

It’s difficult for him to talk about it, he’s not in this position. He just didn’t know what to say, although he wanted to. (AYA Lisa)

He feels really empty after that period, it drained his energy as well. (AYA Emma)

V. Referral Pathway

i. I didn’t know where to go to, or whom to find for my problem

[I want to] get to a platform or somewhere for me to know where I can go for this guy (healthcare provider) and these kind of questions. (AYA Leon)

[I need something that tells me] which people I can go to. Because no one knew. (AYA Lisa)

Because I’m from med school, I do know where to go to: GP and say I’ve got a problem, I wanna talk about it, I know who to talk to, please give me a referral. (AYA Daan)

I called the breast cancer foundation and asked them “Where should I go? I don’t know.” They referred me to this doctor and GP emailed referral. (AYA Lisa)

I really would have wanted them to refer me to one (sexologist), but they didn’t. (AYA Lisa)

I don’t know where to start. I don’t know if it’s the best way to go to my GP. (AYA Emma)

ii. The first step of reaching for help is a burden

Even calling GP is still a burden. (AYA Emma)

Even for Dutch who are really open, it is still a step you need to take [to reach out for an expert about sexuality]. (AYA Lisa)
For actually taking the step there’s a personal burden for me. (AYA Daan)

I do think there’s a boundary, it’s a big step for me to do that (ask for referral). I know I can talk about all these really well, however to act on it is a different thing. (AYA Daan)

**iii. The specialist should be easy to reach**

If I want to go to a sexual specialist, it would be convenient to know if there is one from the same district. I didn’t want to travel just to another place to talk yet again about the problem. (AYA Leon)

Distance is really a big deal, takes a lot of energy. Even after my treatments it’s good to know that I can just knock on the next door. (AYA Leon)

**VI. Sexual Communication**

**i. Intimacy during cancer sees a lot of changes**

I was tired a lot and my libido was lower. But cuddling was nice too... You know, create other ways (to be intimate). (AYA Anne)

It feels normal to not have it, but it’s not normal. (AYA Emma)

During my treatment, I was so ill and my energy was low, so this whole part had really low priority. We don’t even talk about it. (AYA Emma)

A lot changes. It feels differently. You look like an alien. You have no hair, I had one breast, I gained 10kg because of the menopause effect. You don’t feel comfortable. Everything dries up. (AYA Lisa)

**ii. Sex is an emotional and hard topic to start with**

It’s a whole process [working toward good communication], but you need to start somewhere. I need something concrete. (AYA Emma)

We could talk about a lot of things, but this is very hard to talk about, and I’ve noticed that it has become more and more difficult. (AYA Emma)

It (changed sexual needs) was something I felt that I really needed [to talk about with her]. But it was kind of very emotional. (AYA Leon)

I didn’t have many questions, especially not on sexuality. But I do think it’s coming to me when I find a partner. (AYA Daan)

**iii. Relationship can be affected by the lack of sexual communication, or become closer because of good sexual communication**

At one point I (will) think “Okay, we don’t have intimacy anymore. I don’t know where it goes to then.” (AYA Emma)

It actually brought us closer to each other. (AYA Anne)

**VII. Dating and Disclosure**

**i. Cancer made dating harder because of its impact on emotions**

It was very hard for us to not only sexually, but also get emotionally involved if you don’t feel the same every day. (AYA Leon)

I couldn’t handle a girlfriend with me with needs next to cancer. (AYA Leon)

There was something with my hormones. It was really hard to pinpoint what my problem was. I was feeling different all the time. Every day your hormones give you something different. (AYA Leon)

How to deal with my hormones that go up and down all the time? I can deal with it myself. But this is not fun for people around me. (AYA Leon)

**ii. Dating would be difficult with the impact of cancer**

If I didn’t have a relationship, this would be really important. (AYA Emma)
Oh God, dating, no. You’re young. I don’t think guys or girls would like that. (AYA Lisa)

If I were dating, that would have been a difficult institution. (AYA Anne)

Hypothetically if I date, I would be really scared [to disclose]. Maybe if I were really drunk. (AYA Lisa)

Especially (hard) if you don’t have your breasts anymore. (AYA Lisa)

First, when I was diagnosed with breast cancer, the first thought that came to my mind was, “Oh, my God, maybe he doesn’t wanna be my boyfriend anymore, because he wouldn’t want to be with a girl with breast cancer.” (AYA Anne)

Sexually that’s even worse, because you actually just start to date someone, you cannot talk to her about that. (AYA Leon)

iii. Disclosing cancer is confronting and makes me feel vulnerable

I don’t tell everybody about it. It makes you vulnerable. (AYA Daan)

I tell somebody when there’s need for it, or when it’s relevant in the context, if something happening around us would be recognizable for me, which would be hard, it’s like confronting. (AYA Daan)

I don’t like to burden people with it, it’s like dropping a bomb at somebody when I talk about it. (AYA Daan)

iv. I want to disclose it at a good moment

From a certain moment on we can talk about it, but I’ll wait for a good opportunity. (AYA Daan)

She caught me by surprise (bringing up the topic of illness) and I didn’t really like it. (AYA Daan)

I want to be in control of this topic when I tell. (AYA Daan)

VIII. Dealing with Side Effects

i. It’s easier to deal with knowing that it is just temporary

It was easier for me because there’s a deadline to this (side effect). (AYA Leon)

In one week, I already see new (eyebrow) hair growing so I was like, okay, this is just temporary and it’s coming back already. (AYA Anne)

ii. It is hard to be completely emotionally prepared for the long-term changes

It’s tough [to experience hair loss]. You think you can prepare for it, but you never can really. When it happens it means a lot for a woman. You feel like a little boy. It looked horrible. I found myself really ugly. (AYA Emma)

It’s never gonna be the same anymore. It’s never gonna be what it used to be. (AYA Lisa)

iii. Cancer brings worries to AYAs but it is not always necessary

You’re worried so much about your body. Would be helpful to have something to click on to see if it’s side effect, not sweating googling things over there. (AYA Leon)

At that moment (noticing a swollen scar) I just wanted to be in the hospital within 24 hours. I shouldn’t have to worry so much. (AYA Leon)

When I read and I was like, Oh, no, sex will be difficult for the coming five years. But actually, it’s quite okay. (AYA Anne)

When you feel something in your body, this (cancer or side effect) is the first thing that pops in your head. (AYA Leon)

iv. The real impact on sexuality and intimacy starts after the treatment when AYAs start coping with the impacts of cancer
6 months after treatment people think you’re better, but then you start coping with it. And you’re never the same. It has such a huge impact. (AYA Lisa)

I think every young cancer patient will tell you the same, that the hardest part is after your treatments, everybody who survives at my age will say that. (AYA Leon)

As a woman it’s always on your mind [whether it is still possible to reproduce in the natural way]. (AYA Emma)

A part of me thinks in a couple of years, this (fertility issue) is going to have a major influence on my life. (AYA Daan)

v. AYAs need to be reassured that seeking for help about side effects is not overreacting

I go to a psychologist but it felt like I shouldn’t bother. [The thought] “You’re alive. Shut up.” - it hurts you. It is a really big deal, especially when you’re dating. You’re insecure about yourself. (AYA Lisa)

I had more problems when I was ill, and now I have to go to the doctor to speak about this (less serious sexuality issues). (AYA Emma)

I wouldn’t make an appointment just to highlight this subject, maybe I’m thinking that I’m overreacting, or it’s not the biggest problem... especially after the history of being really ill and the treatment was very serious. (AYA Emma)

I kind of feel that people think I make too big of a deal out of it because I’ve been through hard things. It doesn’t seem that important. But it is important. (AYA Leon)

vi. Side effect on the body image impacts feelings and sexuality

Before I lost my eyebrows (being just bald) I can still walk down the street, but when I lost my eyebrows then it’s “Oh there’s a cancer patient”. (AYA Leon)

[After 4 years] my eyebrows are still missing. The way you look interferes with the way you feel and your sexuality. It’s really important to me. (AYA Lisa)

It’s difficult for me to accept the way my breasts are right now. (AYA Lisa)

I had cold hat that froze hair cells. It was helpful for my sexuality. Didn’t make me feel less confident about how I look. I still felt like a woman. (AYA Anne)

vii. Emotional support on coping with side effects is also important besides medical support

Can somebody help me or advice me how to do deal with this (side effect)? Not medically but just emotionally. (AYA Leon)

IX. Relationship to AYAs

i. It is reassuring to hear that other AYAs have similar situations

Her chemotherapy was a bit earlier than mine. And she didn’t have that much side effect. So that was very happy to hear. (AYA Anne)

It made me feel happy and thankful for my situation. (AYA Anne)

ii. Learning about other AYAs’ experiences makes me feel that I’m not alone with my struggles, and that helps me deal with cancer better

Details of the cancer are different. We come from different places. But the emotions are the same. (AYA Daan)

[I’d like to] maybe read some stories about other AYAs. [So I know] you’re not the only one. You’re not weird for having this problem. (AYA Emma)

Would be helpful to read some short AYA stories, so people recognize that others have the same problem. To comfort people that the things they experience with their sexuality during the treatment is not
abnormal. It’s part of the side effect or otherwise psychological. (AYA Anne)

We recognize each other’s story a lot, it’s really interesting. (AYA Daan)

Really helpful to see people just dealing with the same misery. (AYA Leon)

Don’t talk to me, but you can read my story. Probably not even helpful, but every patient says the same thing, and it’s so recognizable. (AYA Leon)

I knew a lot of people in the same phase dealing with the same emotional problems then somehow you feel you can take rest. “Yeah. Okay. Now I’m in this phase. I was warned about it. So be it.” (AYA Leon)

At first I only wanted to connect with people who already survived the treatment and everything and live a happy life now. So I can look forward to that. But halfway treatment, I wanted to have somebody who was just in the same situation as I was. (AYA Anne)

iii. AYAs can form very special bonds

I got a really special person in my life. (AYA Daan)

It makes the bond so much stronger when you talk about things like that (sexuality disturbances). (AYA Anne)

We don’t need that many words to tell each other what hard time we had been going through. (AYA Daan)

iv. AYAs are the ones who truly understand the struggle

People can imagine, but they don’t know what it’s like. That’s especially the case in some moments during the treatment and after that. (AYA Lisa)

The whole cancer thing is really difficult to understand if you haven’t had it. (AYA Daan)

I actually wanted to talk to people who are going thought the same thing and complain a little, people who understand. (AYA Leon)

It’s hard to tell people (who has not experienced cancer) what you’re suffering. (AYA Anne)

X. Sexual Equipment

i. It is hard to find the right equipment

(After trying a lot and finding the right one) I wrote about lubricant [in my blog]. A girl came to me and said it’s amazing. I also told my oncology nurse which lubricant I used, so maybe she can help other people with it. (AYA Lisa)

ii. It is hard to get the equipment

You can’t go to sex shop. It’s too big of a step. They could be in shock also. (AYA Lisa)