

AUTONOMY AND RELATIONS

INVESTIGATING THE ROLE OF SHARED DECISION MAKING
IN YOUNG HEMATO-ONCOLOGICAL PATIENTS

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AIMS



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1. Presenting the topic of my research
2. Presenting the methodology of my research
3. Discussing all of this and hopefully receiving some useful input

TOPICS



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1. Why this topic?
2. Autonomy and relations
3. Target population
4. Study design
5. Literature review
6. Quantitative part
7. Qualitative part
8. Integration and expected outcomes

1. WHY THIS TOPIC?



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1. WHY THIS TOPIC?

For a personal reason:

I know quite well the gentleman on the left side of this picture, and thus the patient's perspective.

For a couple of theoretical reasons:

- The concept and role of autonomy in biomedical ethics had a fast evolution during the last 50 years, actually switching polarity, and this is an interesting fact;

- Benchmarking a practical approach (or a toolkit) to empirical ethics, developing a scalable and reusable research system.



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2. AUTONOMY AND RELATIONS



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FROM THIS...

“The physician who treasures his patient’s life, *without trying to judge its value to the patient, his family or to his community*, will in the end make fewer mistakes, will learn more about the disease he is treating, and will have the satisfaction of giving his efforts against difficult odds”

(Karnofsky 1960, 9–10)



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...TO THIS.

“[...] respect for autonomy—in so far as such respect is consistent with respect for the autonomy of all potentially affected—should be seen as an integral component of the other three of the four principles and thus *should be regarded as first among equals.*”

(Gillon 2003 1960, 311)



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2. AUTONOMY AND RELATIONS

Shared decision making: the way to bring patients' autonomy into the care process

“Of the 418 articles examined, 161 (38.5%) had a conceptual definition of SDM. We identified 31 separate concepts used to explicate SDM, but only “**patient values/preferences**” (67.1%) and “**options**” (50.9%) appeared in more than half the 161 definitions. Relatively few articles explicitly recognized and integrated previous work.”

(Makoul and Clayman 2006)

“[...] an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.”

(Elwyin et al. 2012)



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2. AUTONOMY AND RELATIONS

Context:

Making decisions (connected to health care)

Stakeholders:

Patient

Physician

Aims:

- Understanding the choice to be made and its consequences
- Sharing evidence and information
- Considering different options
- Supporting patients along the process
- Achieving informed preferences

(Elwyn et al. 2012)



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2. AUTONOMY AND RELATIONS

More than the “Autonomy Imperative”

A Cochrane review (Stacey et al. 2017) including 105 studies (RCTs) on decision aids as tools to improve shared decision making found out the following effects:

- Better knowledge of options and outcomes;
- More accurate perceptions of outcome probabilities;
- Help people feel more comfortable with their choices than usual care;
- Positive effect on the patient-clinician consultation.

(Stacey et al. 2017)



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BUT STILL SOMETHING/SOMEONE IS MISSING

The autonomous man is—and should be—self-sufficient, independent, and self-reliant, a self-realizing individual who directs his efforts toward maximizing his personal gains.

(Code 1991)



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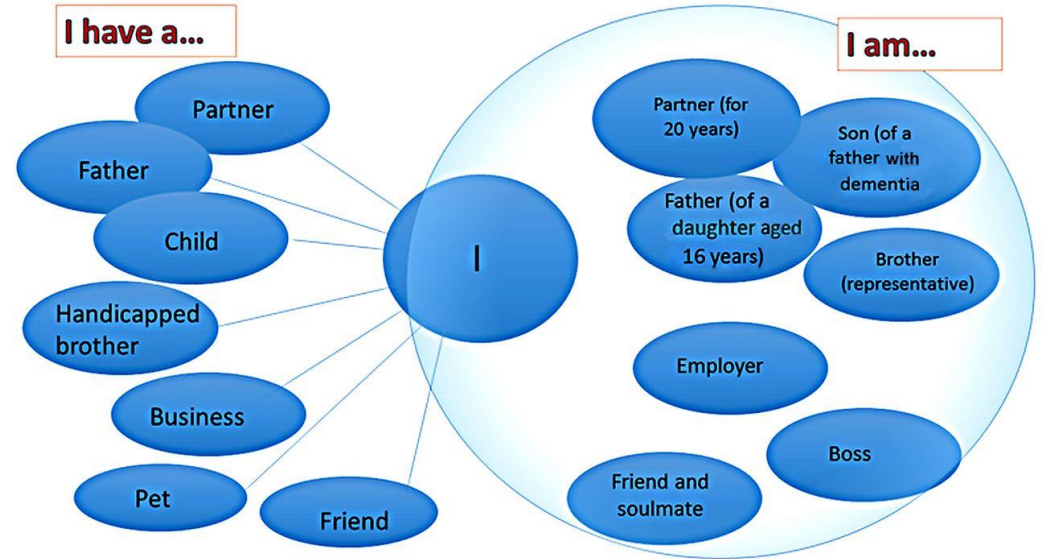
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2. AUTONOMY AND RELATIONS

Others as a constitutive part of our identity

In light of Ricoeur's hermeneutics of the self, our view of relations shifts from 'having' a partner and a family to 'being' a partner and a family member. In everyday language, we may be used to think of our relations as things that we 'have'. But Ricoeur's philosophy transfers this relational connectedness (including the tensions that are involved) from the outside to the inside of the self.

(van Nistelrooij et al. 2017)



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2. AUTONOMY AND RELATIONS

Jake, a **10-year-old boy** with recurrent **leukemia**, had not responded to the last possible curative treatment for his disease. Jake (not his real name) was experiencing **uncontrolled bone pain**. The second-year oncology fellow, Dr Adams (another pseudonym), was well trusted by the family and had been very involved in Jake's care throughout his illness. Now, Dr Adams has consulted the palliative care service about both pain management and for help with decision-making at this turning point for the patient. Dr Adams was distressed about meeting with the family. At the last family meeting, when they were **considering whether to try 1 last, highly toxic regimen of chemotherapy or instead shift to a palliative treatment plan**, Dr Adams had felt **conflicted about how to handle the parents' direct question** regarding what they should do. She wanted to be compassionate and supportive of the family but **did not want to violate the parents' autonomy** by making a strong recommendation of whether they should enroll Jake in a Phase I trial that had a low likelihood of extending Jake's life or transition at this point exclusively to comfort care. The parents were giving signals to the team that they did not want to make the final decision about how to proceed. They were clearly emotionally distraught. Given Dr Adams' concerns about guidance in decision-making, the palliative care team recommended an ethics consultation to determine the ethically appropriate range of actions by the medical team.

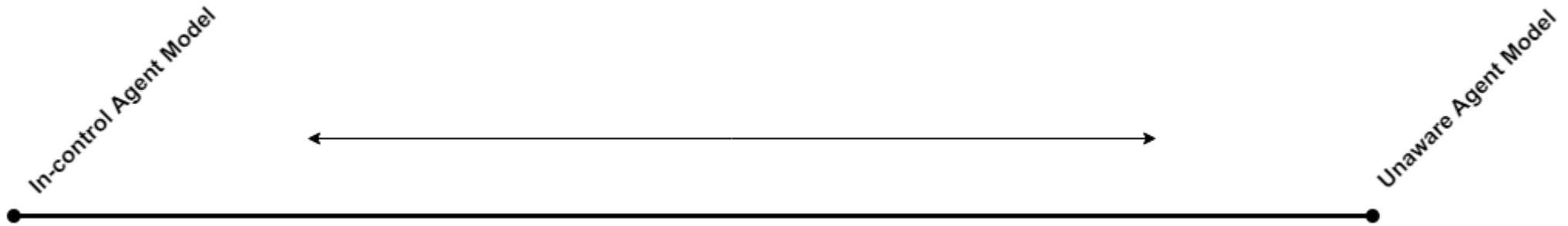
(Walter and Friedman Ross 2014)



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2. AUTONOMY AND RELATIONS



There is a broad spectrum of possibilities in real life between the two poles of solipsistic autonomy and no autonomy (especially when considering also children and adolescents).

(Degner, Sloan and Venkatesh 1997)



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BALANCING BETWEEN SELF-DETERMINATION AND PATERNALISM

[...] autonomy as moral competency should get rid of its individualistic connotations. Instead a notion of relational agency should be introduced as underlying the concept of autonomy

(Verkerk 2001)



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2. AUTONOMY AND RELATIONS

A care ethics approach to autonomy: some questions

- Does relational autonomy have a **solid theoretical framework**?
- What are the boundaries between **support and undue influence**, especially considering a realistic agent model?
- Who are the **involved stakeholders**, and what **morally legitimizes** their involvement?
- How does relational autonomy work in the context of some **serious disagreement** between the stakeholders?
- Besides the theoretical justifications, is it possible to **find empirical evidence** proving relational autonomy as an ameliorative instrument?
- Is a relational approach to autonomy a **viable tool to ameliorate shared decision making**?
- How can or should relational autonomy based **SDM implemented in clinical practice**?



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3. TARGET POPULATION



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3. TARGET POPULATION

- Persons with a hemato-oncological disease (ICD-10: C81, C82-86, C96, C90, C91-95, C91, C92-94)
- Age between 15 and 34
- Living in Switzerland

The patients' point of view (literally)



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WHY THIS TARGET POPULATION?

- The most common kind of neoplastic disease affecting adolescents and young adults;
- These patients face severe conditions, but they are not "on a fixed track";
- That age interval is widely adopted in literature and is used by NICER;
- The amount of choices to face and their impact is relevant;
- Young people are generally highly embedded in a relational context, primarily with their family.



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3. TARGET POPULATION

Prevalence

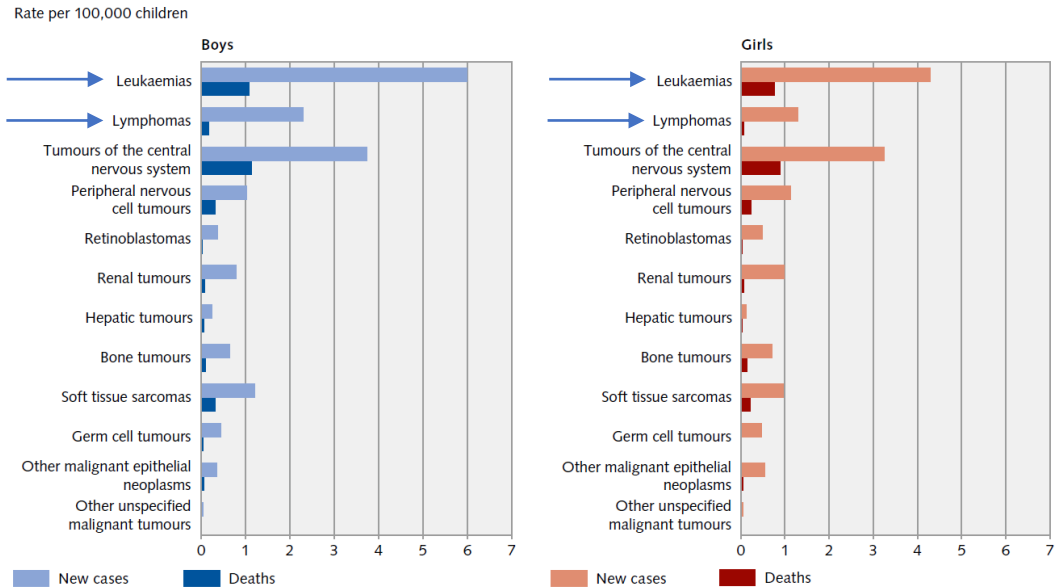
Leukaemias occur most frequently (34% of all types of cancer), followed by tumours of the central nervous system (primarily brain tumours, 21%) and lymphomas (11%).

(Arndt et al. 2016, 125)

Childhood cancers by tumour group, 1993 - 2012

Childhood cancers by tumour group, 1993–2012

G 5.2



Source: SCCR – New cases; FSO – Deaths

© FSO, Neuchâtel 2016



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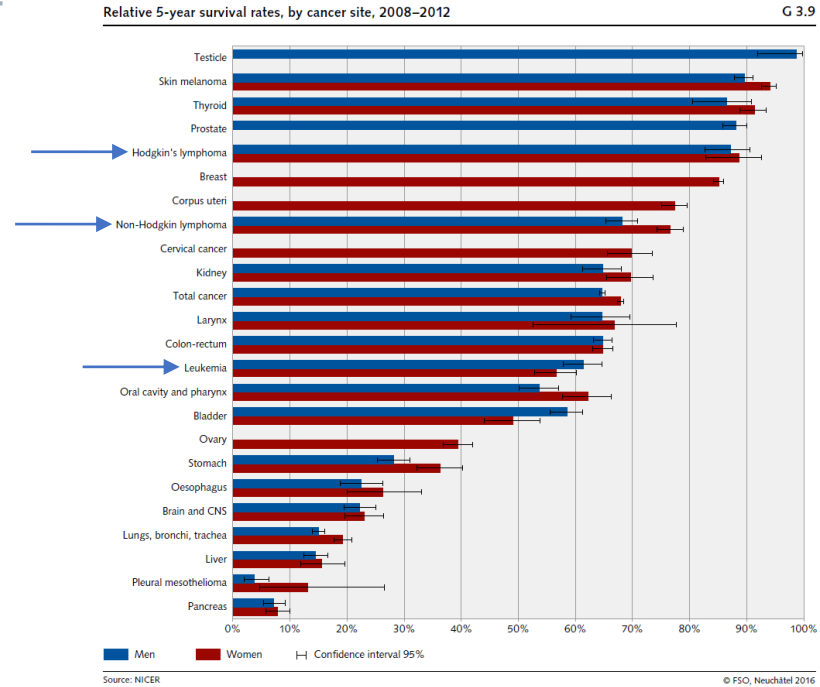
3. TARGET POPULATION

Survival rates

The survival rate at five years from the diagnosis is between 80% and 90% for Hodgkin’s lymphoma; 65% and 75% for non – Hodgkin’s lymphoma; 55% and 65% for leukaemia.

(Arndt et al. 2016, 20)

Relative 5-year survival rates, by cancer site, 2008-2012



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3. TARGET POPULATION

Deciding on what?

The decisions are not limited to **medical treatment** but also involve **personal, social and professional life**, often having an impact on others. Relationships tend to gain high relevance for a person facing hard choices because of a life-threatening medical condition. At the same time, relational tensions can arise from the confrontation with the needs, expectations and experiences of all the stakeholders involved in the care/cure process.

(Renzi et al. 2016, Gargiulo et al. 2017)

Yummy! my first irradiated platelets.



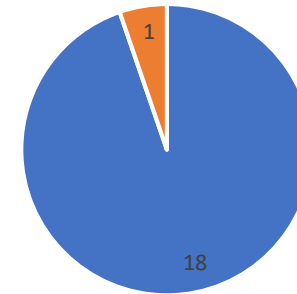
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3. TARGET POPULATION

How did you face the decisions involved in the therapeutic process?



■ assisted by someone ■ alone

Some preliminary data

A (very!) preliminary survey on a convenience sample (19 Italian patients with a hemato-oncological disease, aged between 17 and 67, median age of 34, 10 males and 9 females) shows that the vast majority of them involves someone in their decisions...

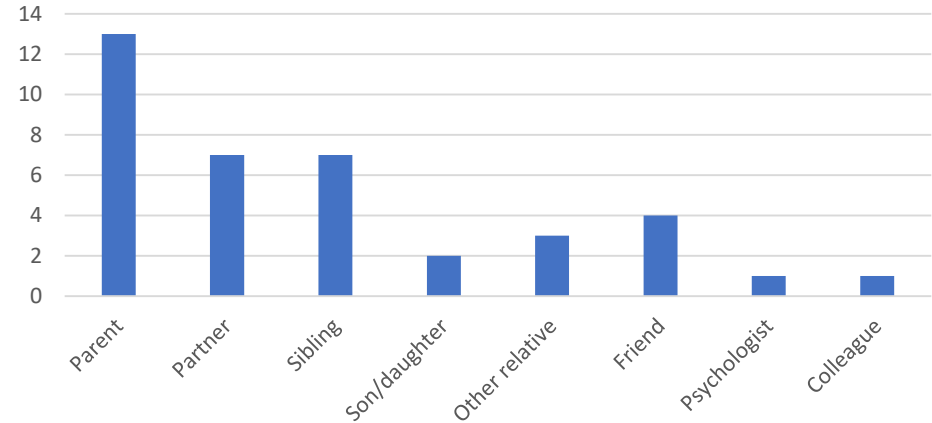


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3. TARGET POPULATION

Who supported you in making the decisions involved in the therapeutic process?



... And that the persons involved the most are family members (multiple answers were allowed).



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3. TARGET POPULATION

Choices

Whether to **try an experimental therapy** before doing the transplant, and accepting the transplant despite the fact that there was a medium/high probability of death.

Getting the courage to **leave my job**

The choice of **study/work sites**, the choice of **the partner**, the choice of **the job**

To **start a bachelor** despite the chemotherapy to be started.

The choice, far from trivial, to **start some paths that I knew I could not complete** or at least that I should pause in the period before the bone marrow transplant.

...



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3. TARGET POPULATION

...

Choose the **path of treatment**

Receiving a bone marrow transplantation from my mother, and **having to take drugs** that could have compromised the positive result of the transplantation

Leaving my own business all of a sudden to take care of my life

Trying to **protect my loved ones** from my problems and from my sometimes exaggerated and irrational reactions

Live or die

Decide to **do the last two cycles of chemotherapy in day hospital**, going back and forth every day.

Enter a clinical trial that entailed relatively high risks



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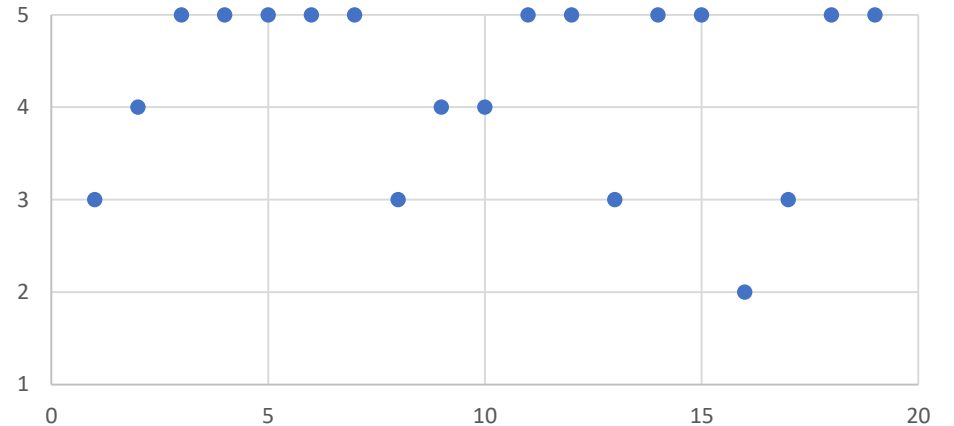
3. TARGET POPULATION

Likert scale, 5 = very much; 1 = not at all

Median = 5, Mean = 4,26

Possible correlation (to be tested with a broader dataset) between the perception of impacting others and the age at diagnosis

Do you think that your decisions had an impact on the lives of who is close to you?



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3. TARGET POPULATION

Impact

My wife and I **can't have children**.

My wife had to **keep the family up** (we have two children), emotionally, organizationally and economically.

Having decided to go to university in spite of everything involved a great effort for my parents **to take me to the lessons** when I could not go alone.

My partner changed course of study after a difficult time during my illness.

My parents had to leave work to assist me, they had to accompany me everywhere and my mother had to change the way of cooking. She also had to sanitize the rooms, making it more maniacally and every day.

...



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3. TARGET POPULATION

...

The disease imposes HER times, and you have to comply with them. Although for a limited period of time, it was necessary to **change times and habits**.

Since I needed a person who was always close to me, I **moved to my parents' house** on chemotherapy days.

I believe that **the way I dealt with the disease has helped a lot the people around me**. I didn't have to make any particular choice.

The life of my family has changed completely: **habits and rhythms of life**.

Obviously, when a person falls ill, especially if he or she is a minor, he or she forces the family and those close to him or her to a **radical change**.



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4. STUDY DESIGN

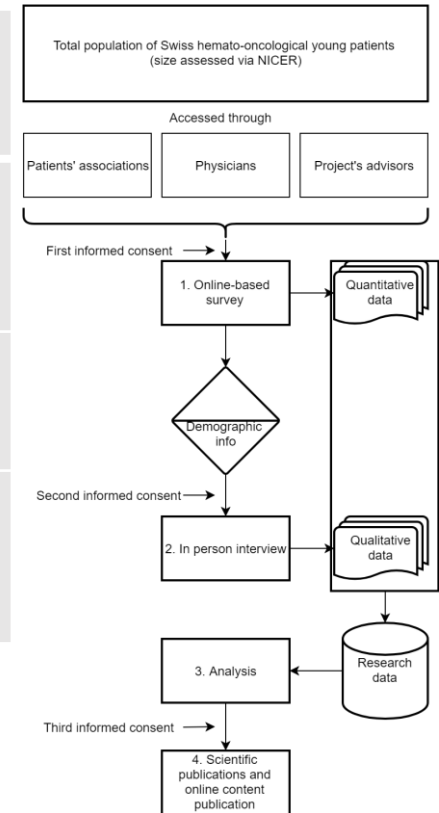


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4. STUDY DESIGN

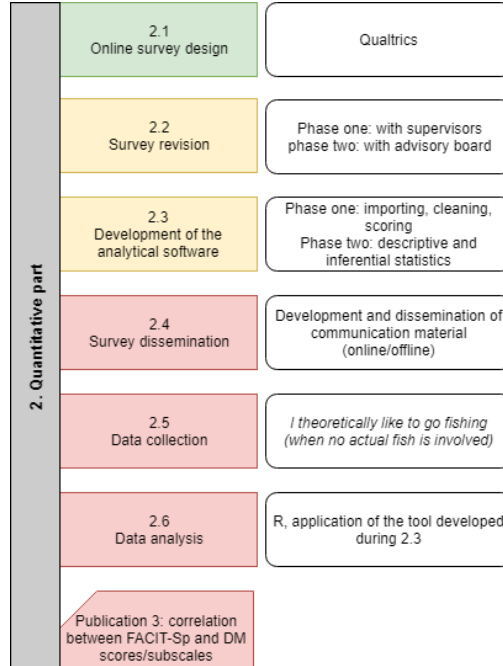
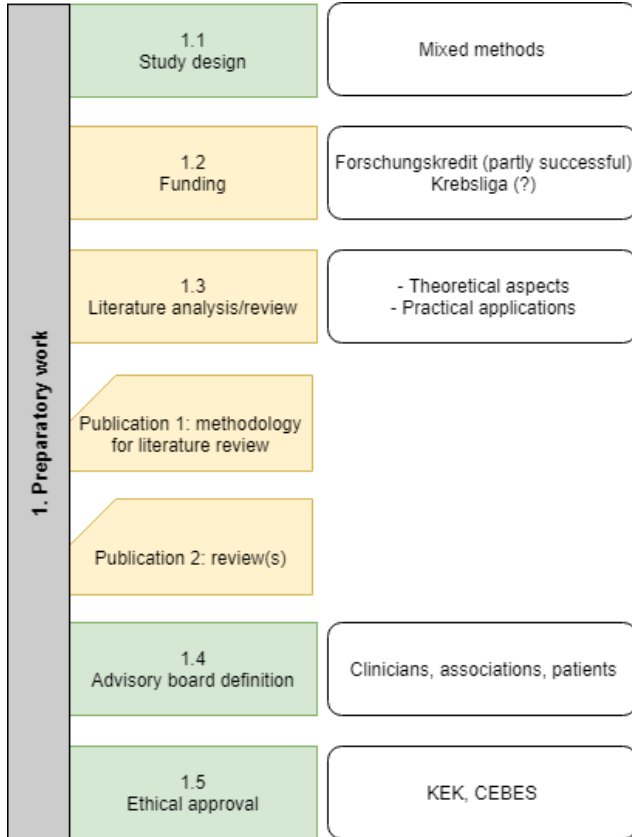
Issue	Instrument
<ul style="list-style-type: none"> - Theoretical solidity of the relational autonomy model; - Screening and evaluation of eventual implementations. 	<p>Critical analysis of the medical and bioethical literature on autonomy, relations and (shared) decision-making.</p>
<ul style="list-style-type: none"> - Evaluation of quality of life, decision making style and demographics of the target population. 	<p>Online survey on perceived quality of life of the study population (in particular regarding decision making and autonomy).</p>
<ul style="list-style-type: none"> - Fine grained assessment of the issue at stake (who to involve, how, what happens in case of conflicts, ... (see slide 17)). 	<p>Qualitative analysis of in-depth, narrative interviews on patients' subjective experience, using standard DIPEX methodology.</p>



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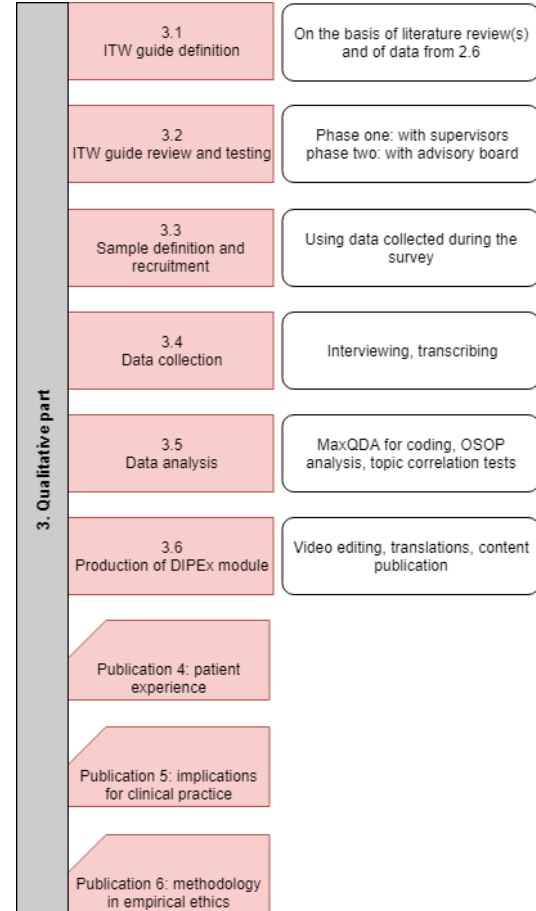
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4. STUDY DESIGN



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5. LITERATURE REVIEW



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5. LITERATURE REVIEW

Block 1. Context

Hemato-oncological (patients/diseases)

AND Block 2. Age group

Adolescents and young adults

AND Block 3. Practice

Shared decision making

AND Block 4. Language

English

In PubMed syntaxis:

```
(
(hematolog*[TiAb] OR haematolog*[TiAb] OR hemato-oncolog*[TiAb] OR haemato-oncolog*[TiAb]) OR
(hematology[mh] OR hematologic diseases[mh])
)
AND (
(adolescent*[TiAb] OR teenager*[TiAb] OR "aya"[TiAb] OR "young adult"[TiAb] OR "young adults"[TiAb]) OR
(adolescent[mh] OR adult[mh])
)
AND(
((Shar*[OT] OR Inform*[OT] OR Collaborative[OT]) AND (decision*[OT] OR deciding[OT] OR choice*[OT] OR
care*[OT])) OR ((Decision*[OT] OR Choice*[OT]) AND (Making[OT] OR Make*[OT] OR Support*[OT] OR
Behaviour*[OT] OR behavior*[OT])) OR ((patient*[OT] OR consumer*[OT]) AND (participat*[OT] OR involv*[OT]))
OR (Decision Making[mh] OR decision support technique[mh] OR decision support systems, clinical[mh] OR
choice behaviour[mh] OR Personal Autonomy[mh] OR Freedom[mh] OR professional-patient relations[mh] OR
patient participation[mh]) OR ((nurse*[OT] OR physician*[OT] OR clinician*[OT] OR doctor*[OT] OR "general
practitioner"[OT] OR "general practitioners" [OT] OR gps[OT] OR "health care professional" [OT] OR "health care
professionals" [OT] OR "healthcare professional" [OT] OR "healthcare professionals" [OT] OR "health care
provider"[OT] OR "health care providers" OR "healthcare provider" [OT] OR "healthcare provider"[OT] OR
resident*[OT]) AND (patient*[OT] OR consumer*[OT] OR people[OT]) AND (relation*[OT] OR communicat*[OT]
OR exchange*[OT]))
)
AND Eng[La]
```



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5. LITERATURE REVIEW

Screening 943 results

Included literature are being categorized, dividing papers presenting interventions and conceptual/theoretical papers.

The two categories will then be analyzed and condensed in two distinct reviews:

- One on the theoretical models for relational autonomy;
- One regarding its implementation in practice.

Inclusion/exclusion criteria in a nutshell

Inclusion Criteria

Considered population:

- adolescents/young adults (16-35)
- affected by a hemato-oncological disease (ICD-10 from c81 to c96)

AND

Topic:

- considers shared decision making or patient empowerment
- considers decision-making related supportive needs of the population

AND

Type of study:

- original research (quantitative and qualitative)
- review articles
- clinical case studies
- clinical trials
- conceptual and theoretical papers

Exclusion Criteria

- does not meet inclusion criteria
- not in English
- full text unavailable



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6. QUANTITATIVE PART



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6. QUANTITATIVE PART

The survey

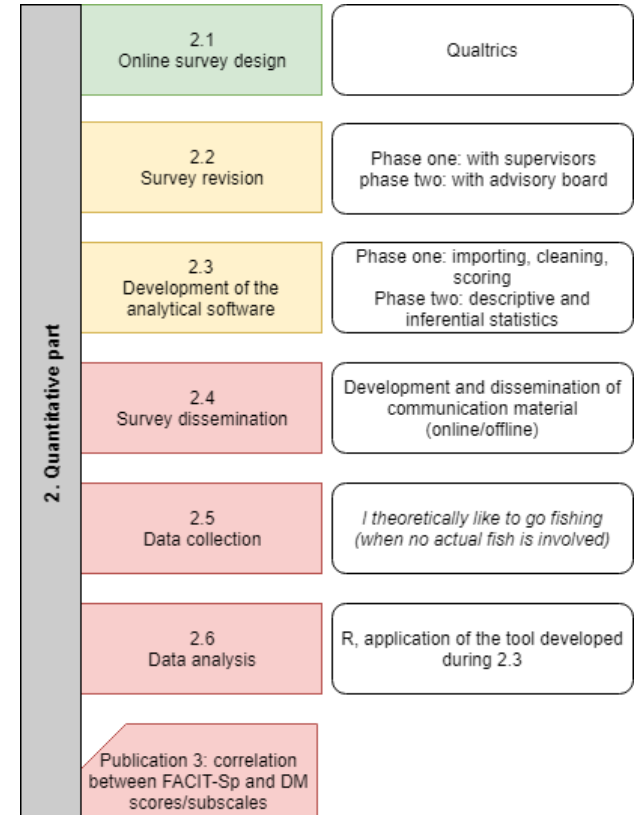
- Realized with Qualtrics (safe, reliable, online-based, multilingual)
- Adaptive consent, contact information, willingness to participate to the qualitative part (14 questions)
- FACIT-Sp (39 items, Likert 5 point scale, divided in 5 subscale blocks), Peterman et al. 2002
- Information about the illness (4 items)
- IIPSS, general purpose measure of dispositional preferences for independent and interdependent problem-solving (10 items, Likert 7 points scale), Rubin et al 2012
- Demographics (8 items)

Where I am standing right now




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6. QUANTITATIVE PART




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English ▾

Giovanni Spitalè presents the module on Young Hemato-oncological patients. Subtitles (EN, DE, FR, IT) available.

Young Hemato-oncological Patients
DIPEX.ch Module Presentations



INFORMED CONSENT
Hello! We warmly invite you to participate in our research project, **DIPEX YHP**.

Purpose:
We would like to explore and understand the experience of **adolescents and young adults (15-34) with hemato-oncological diseases**, with the aim of understanding how to **improve the cure/care process**, and to do so your personal insight on the disease would be really helpful.

The Project:
This project is carried out by the **Institute of Biomedical Ethics and History of Medicine, University of Zurich**. It is part of a long-term study, on whose website people who may be going through a similar health experience can find out **how other people live with it**. It is also available for **training** and further **education purposes**: medical students, health care professionals and people who work in the health care system can better comprehend what patient's experience are and what is important to them.

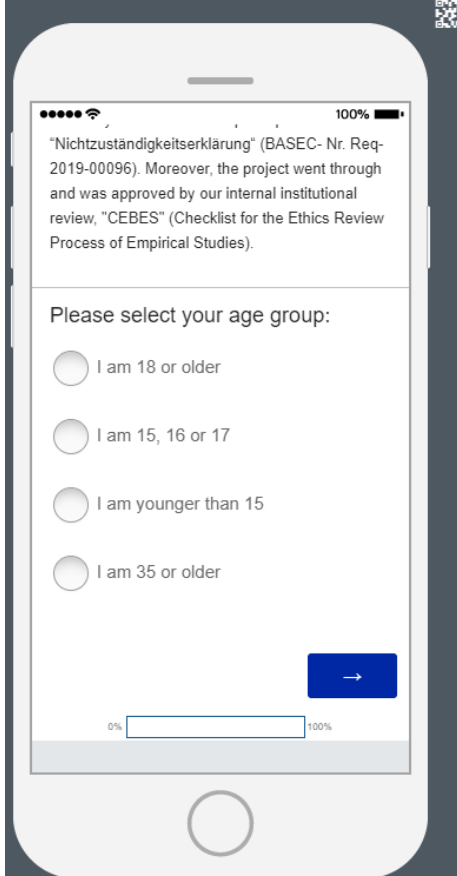
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Optimized for mobile



100%

"Nichtzuständigkeitserklärung" (BASEC- Nr. Req-2019-00096). Moreover, the project went through and was approved by our internal institutional review, "CEBES" (Checklist for the Ethics Review Process of Empirical Studies).

Please select your age group:

- I am 18 or older
- I am 15, 16 or 17
- I am younger than 15
- I am 35 or older

0% 100%

6. QUANTITATIVE PART

Sampling and recruitment:

Multiple snowballing chains started with the help of Krebsliga, Istituto Oncologico Svizzera Italiana, Swiss Hematological Society.

NICER - National Institute for Cancer Epidemiology and Registration has provided basic epidemiological information that will be used to assess the representativity of the sample.

Adaptive consent:

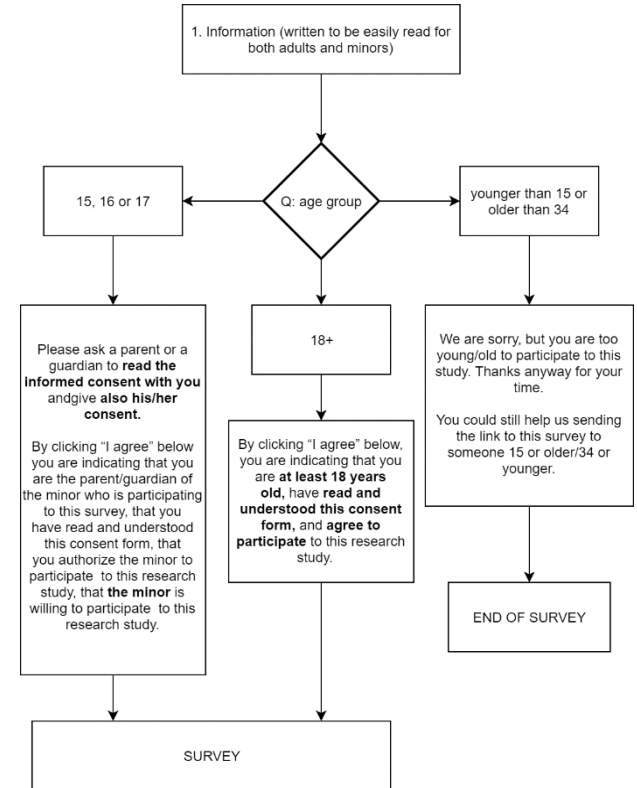
Some of the participants will be minors. Therefore, after a common participant information text written in plain language and explained in a video (with subtitles in 4 languages), the consent system will change according to the age of the potential participant.

The consent process in a nutshell



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6. QUANTITATIVE PART

General aims:

- Provide a useful insight to develop a better focused interview guide for the qualitative part.

Descriptive aims:

- Provide an overview of the quality of life of the target population;
- Provide an overview of the decision making style of the target population;

Inferential aims:

- Test eventual correlations between quality of life and decision making style (hypothesis: a positive correlation may exist between a relational decision making style and a high quality of life).

PROBLEM: is a statistical inference drawn between results of validated and partly validated questionnaires (FACIT is validated in each language, IIPSS is validated only in English) a legitimate conclusion?



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6. QUALITATIVE PART



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7. QUALITATIVE PART

A blurred and nebulous future:

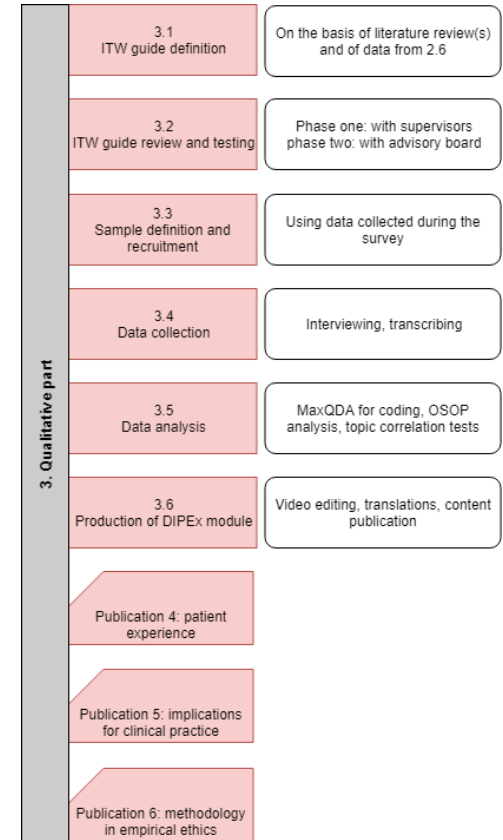
The definition of the interview guide depends on the results of the quantitative part (and also on the literature review).

There will be a first section asking for an open narrative, followed by some more in depth specific questions on autonomy, relations, and making choices.



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7. QUALITATIVE PART

Maximum variation/theoretical saturation sampling:

Participants from the qualitative part will be purposefully selected from the respondents of the survey to define a maximum variation sample, aiming to include every possible variation of the personal experience.

Interviews will be coded and analyzed as soon as possible, in order to keep checking the level of theoretical saturation.

Sampling criteria



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Illness	Demographics	Decision making	FACT-Sp
Time since diagnosis < 1 year 1 to 5 years > 5 years	Age - 15-19 - 20-24 - 25-29 - 30-34	Supporting person - no support - partner - sibling - parent - other relative - friend - other non relative - medical personnel	Sp12 total subscale score - score range 0-15 - score range 16-32 - score range 33-48
Treatment condition - inpatient - outpatient - in remission - not treated for other reasons	Gender - female - male - other	Autonomy - individual autonomy - patient-physician autonomy - patient-caregiver autonomy - patient-caregiver-physician autonomy - autonomy quality score - autonomy satisfaction score	FACT-G total score - score range 0-35 - score range 36-72 - score range 73-108
	Language - German - French - Italian - English		
	Ethnicity - Swiss (German) - Swiss (French) - Swiss (Italian) - European - Other		
	Education - compulsory - upper secondary - bachelor or master - PhD		
	Marital status - single, never married - married or domestic partnership - separated - divorced - widowed		
	Children - has children - does not have children		
	Living arrangement - alone - with spouse or partner - with parent/s - with grandparent/s - with sibling/s - with other relative/s - with other nonrelative/s		

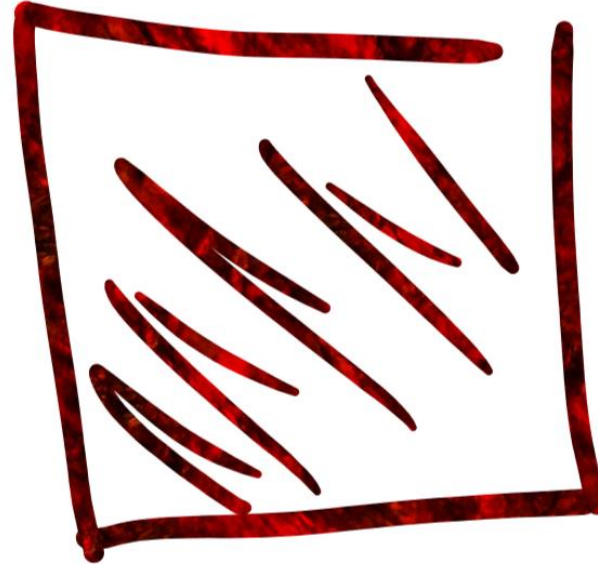
8. INTEGRATION AND EXPECTED OUTCOMES



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8. INTEGRATION AND EXPECTED OUTCOMES



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8. INTEGRATION AND EXPECTED OUTCOMES

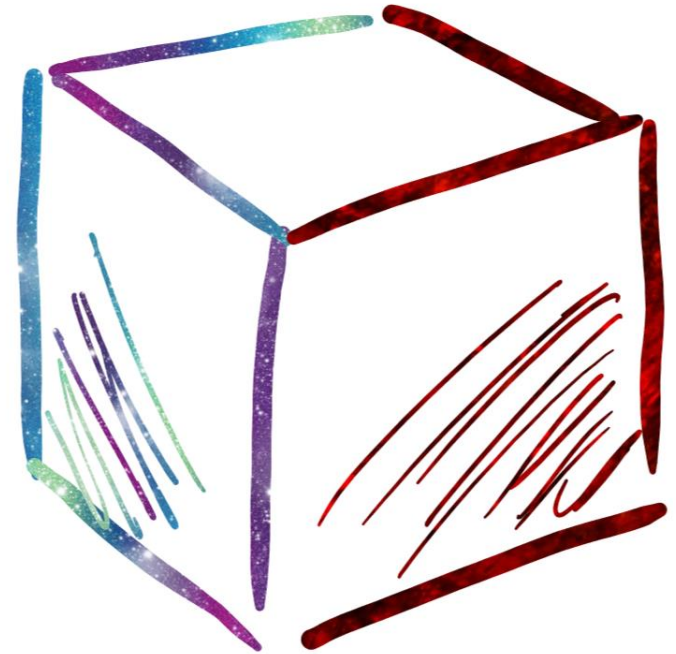
Relevance for cancer specific health services:

This patient group displays a **lower desire for participation** in comparison to people affected by other neoplasias (Ernst et al. 2013).

Nevertheless, hemato-oncological patients **deserve an adequate analysis** of how they can **best be engaged** in their care and in the decisions to be taken (Paper 2002).

Adequate instruments are needed that support a move towards a patient-centred model, assuming a relational environment where autonomous choices by necessity have an impact on others, and others have an impact on these decisions.

This study design aims to address this need, providing a complete perspective on both **magnitude and meaning** of the issue.



A multifaceted view of a complex phenomenon



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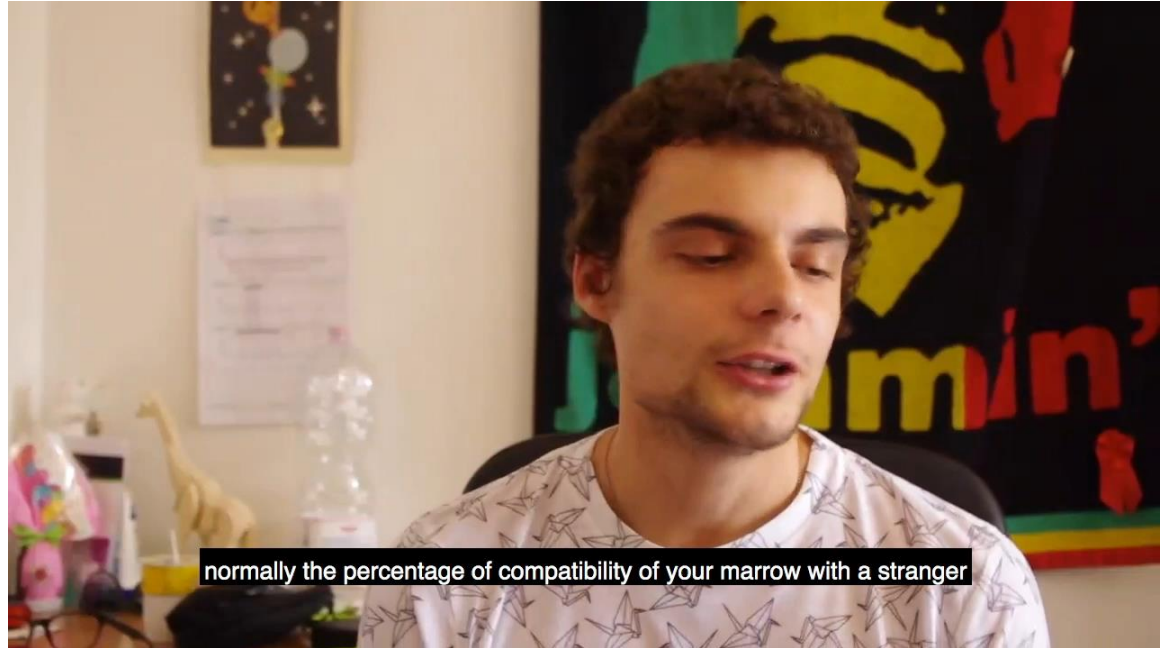
8. INTEGRATION AND EXPECTED OUTCOMES

DIPEX content:

The patient experiences collected will become a module for the Swiss branch of the international DIPEX project. DIPEX is a tool for patient empowerment and medical education (Ziebland and McPherson 2006).

Selected videoclips of the interviewees will be uploaded on the website www.dipex.ch in order to serve as a source of insight and decision support for patients, relatives and care providers, stimulating improvements in this healthcare domain.

An example taken from a pilot interview

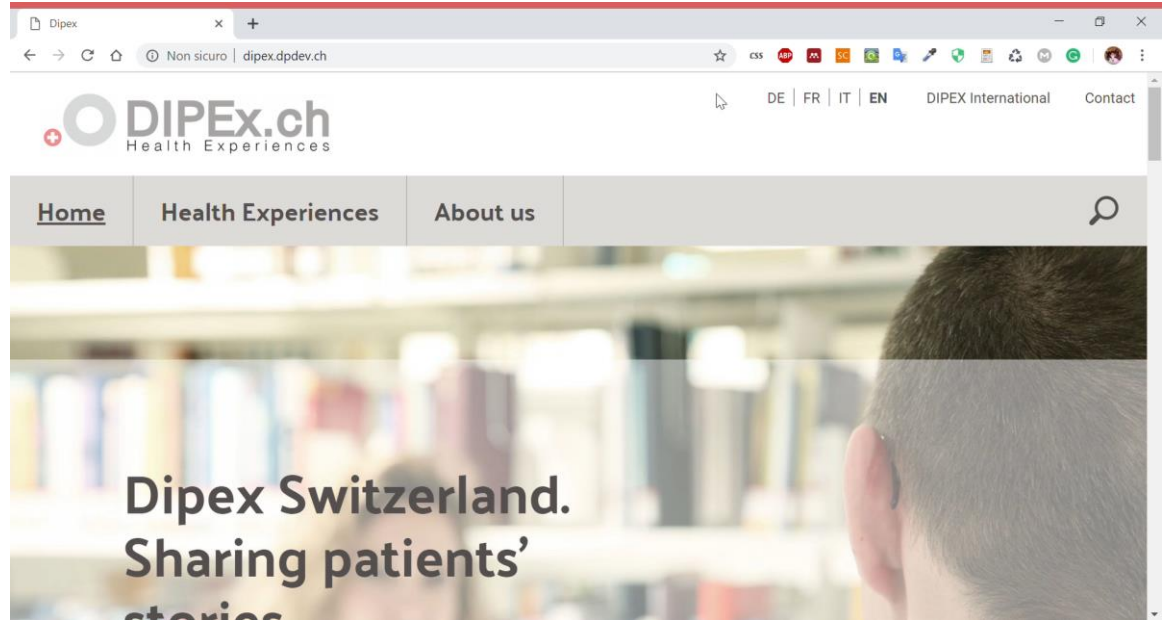
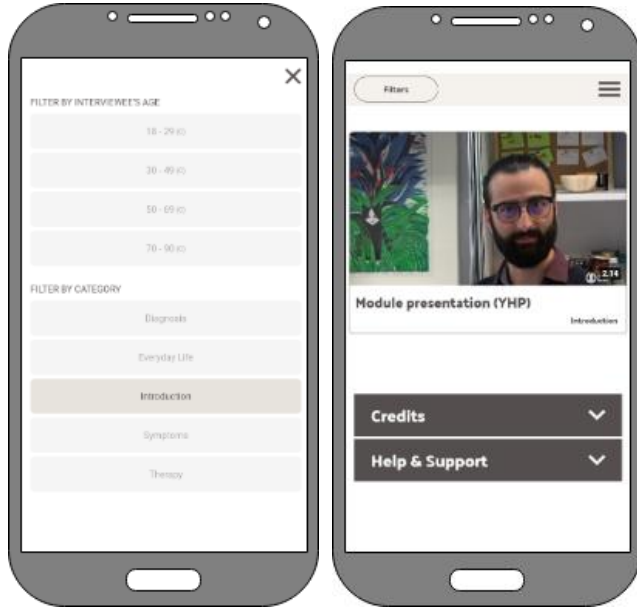


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SO LONG, AND THANKS FOR ALL THE FISH.

(AND DON'T FORGET YOUR TOWEL)



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