



**University of  
Zurich<sup>UZH</sup>**

**Institute of Biomedical Ethics and History of Medicine**

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## **Welcome and introduction**



**Universität  
Zürich<sup>UZH</sup>**

Digital Society Initiative



## **Excellence in Patient Care Symposium 2021**

**The Swiss Database of Individual Patient  
Experiences (DIPEX.ch)**



08.45	Registration
	Livestream
09.00	Welcome and introduction (E, G)
09.15	Keynote 1: Health Experiences Research for Patient Benefit (E) Prof. Sue Ziebland, University of Oxford, UK
09.45	Keynote 2: Patient experiences, health competency, and quality standards (G) PD Dr. Peter Berchtold, Swiss Patient Organization SPO, Switzerland
10.15	Coffee break
	Livestream
10.30	DIPEX.ch – a new resource for the Swiss healthcare system (E) Prof. Nikola Biller-Andorno, University of Zurich, Switzerland
11.00	DIPEX module «Living with dementia» (G) lic. rer. soc. Andrea Radvanszky, University of Zurich, Switzerland
11:45	Discussion
12.00	Lunch break



## Program

13.15	Workshops (G) [only onsite] Introduced by Prof. Andrea Glässel, Zurich University of Applied Sciences, Switzerland
13.30	Parallel workshop 1: The potential of DIPEX for better understanding healthcare needs (G) Parallel workshop 2: The DIPEX database and NLP approaches to analysis (E) Parallel workshop 3: DIPEX, decision aids and (continued) education (G)
14.30	Coffee break
14.45	Presentation of workshop results and plenary discussion (E, G) [only onsite]
Livestream	
15.15	Panel: Harnessing patient experiences for excellence in patient care (G) Moderated by Prof. Christoph A. Meier, University Hospital Zurich, Switzerland
15.45	Joint outlook (G)



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# DIPEX.ch – a new resource for the Swiss healthcare system



DE | FR | IT | **EN**    DIPEX International

Home

Health Experiences

About us

Research

Contacts

**Dipex Switzerland.  
Sharing patients'  
stories.**





## A short history of DIPEX.ch

- Early deliberations regarding a Swiss DIPEX chapter (→ Careum)
- IBME team training at Oxford and through German DIPEX team (→ krankheitserfahrungen.de)
- Development of website, SOPs, database structure, participant information and consent forms, approval REC (nationwide) and data protection
- First grants received for developing DIPEX modules (Alzheimer Schweiz, MS Society, Swiss Cancer Research, Käthe-Zingg-Schwichtenberg-Fonds etc.)
- Swiss DIPEX chapter approved through DIPEX International - ZHAW as founding partner
- Constitution of Advisory Board, kick off meeting July 21



## **Advisory Board**

Prof. Irene Abderhalden, Hochschule Soziale Arbeit FHNW, Olten

Paula Adomeit, Direktorin Pflege, Inselspital Bern

Karine Begey, stv. Direktorin Alzheimer Schweiz, Bern

Prof. Jacques Cornuz, Ärztlicher Direktor, Unisanté Lausanne/Dr. Marie-

Anne Durand, Adjointe Scientifique

Prof. Luca Crivelli, Università della Svizzera italiana, Lugano

Daniela de la Cruz, Geschäftsführerin Krebsliga Schweiz, Bern

Susanne Hochuli, Präsidentin SPO Patientenschutz, Zürich

Prof. Antje Horsch, Institut universitaire de formation et de recherche en  
soins, CHUV / UNIL, Lausanne

Prof. Sabina Hunziker, Leitende Ärztin Medizinische Kommunikation,  
Universitätsspital Basel

Dr. Jacqueline Martin, CEO Careum Hochschule Gesundheit, Zürich

Prof. Arnaud Perrier, Ärztlicher Direktor, Universitätsspital Genf

Prof. Daniel Scheidegger, Vizepräsident SAMW, Bern

Liliane M.W. Waldner, Dipl. Betriebswirtin, Patientenvertreterin, Zürich



## Modules

1. Individuals living with dementia and their relatives (*Swiss Alzheimer Association*)
2. Experiences with COVID-19 (*international module*)
3. Living with chronic pain (*collaboration with DSI*)
4. Intensive care from the perspective of patients and family (*KZS/SAMS*)
5. Talking about live with Multiple Sclerosis (*Multiple Sclerosis Society*)
6. Pregnancy and prenatal testing (*Collegium Helveticum*)
7. Experiences of Parkinson and its treatment (*La Caixa Barcelona*)
8. Decision-making in young hemato-oncological patients (*UZH FK+ SCR*)
9. Mental health (*Schwyn Foundation, PI A. Maatz/Y. Ilg*)
10. Living with a rare disease (*URPP RD, UZH*)

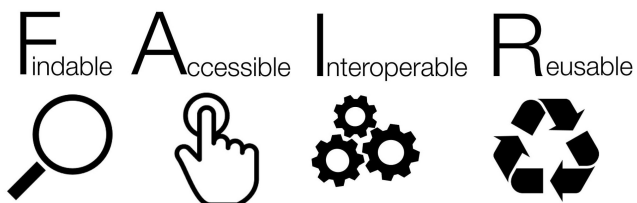
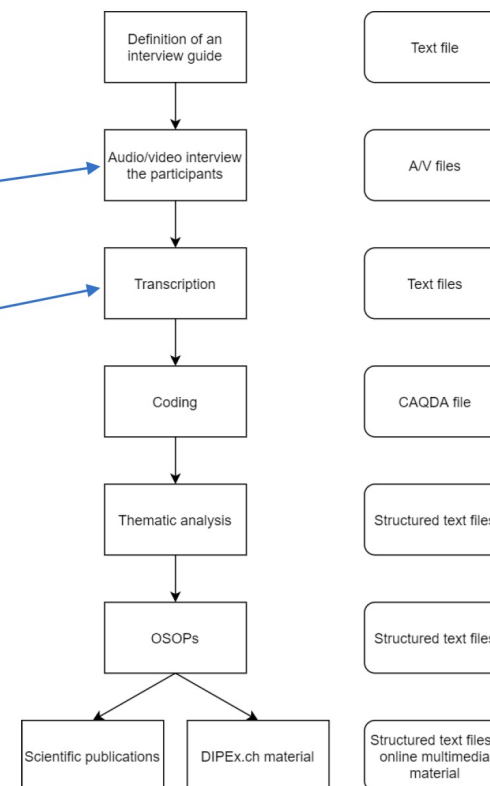
Ideas for future modules: domestic violence, sexual abuse, transplantation, cannabis use, persons after suicide attempt, health care for migrants,...



## The database

1st informed consent  
The interviewee allows the research team to record the interview (A or V). The material is fully available for research and teaching.

2nd informed consent  
The interviewee revises the transcript and specifies their preference about the online use (yes / only specific parts / no) + (video / audio / text )







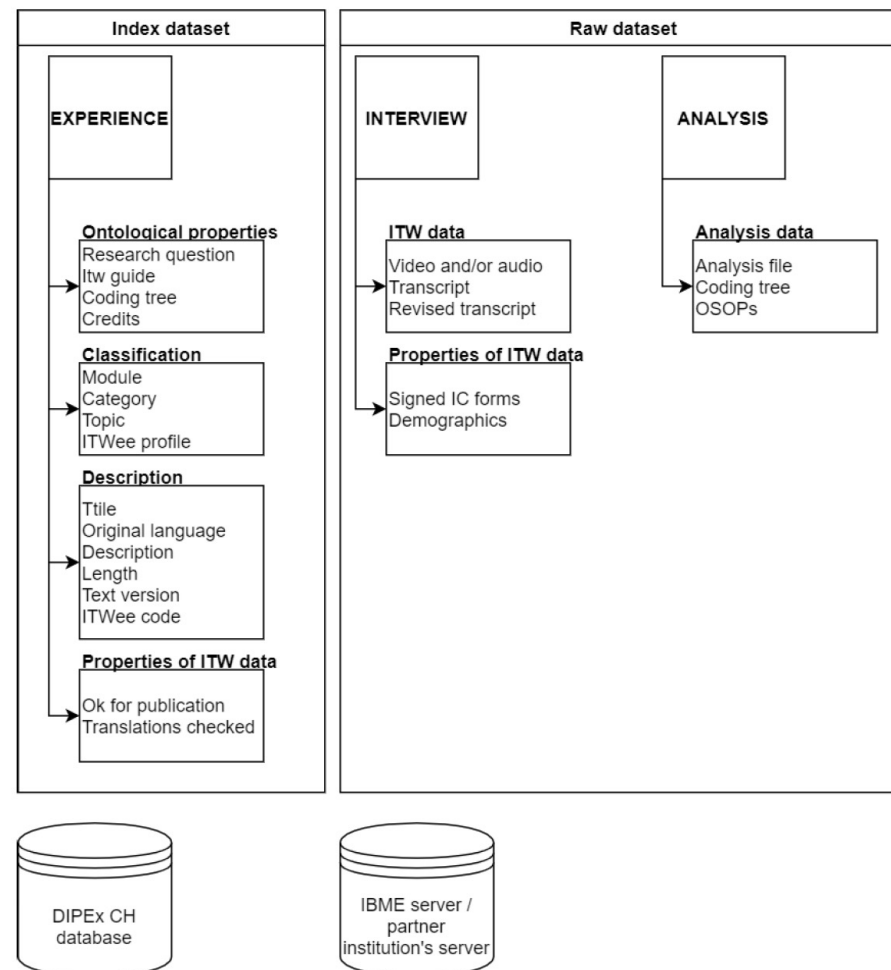
## The database

Raw dataset

The DNA of our research data; located on IBME's servers

Index dataset

The index and mRNA of our research data (extended metadata); located on UZH's MariaDB instance





## Example: Patient experiences – valuing patient perception

*Context: experiences in rehabilitation clinic after period of exacerbation of MS*

“So, there was this situation when I had severe pain and a nurse had this measuring instrument, with which they can measure the pain to see if the physician can continue with the intervention, I don’t know exactly. In any case, the pain showed on her apparatus and the physician looked at it and said: «O yeah, it does hurt you objectively.» And I thought: How stupid is this? I’m hurting, even when it does not show on your apparatus. (...) But if you cannot see it, when it’s just subjective experience, they treat it like: «Oh well...»...”

*(Translation NBA)*



## Example: Patient experiences – the importance of social care

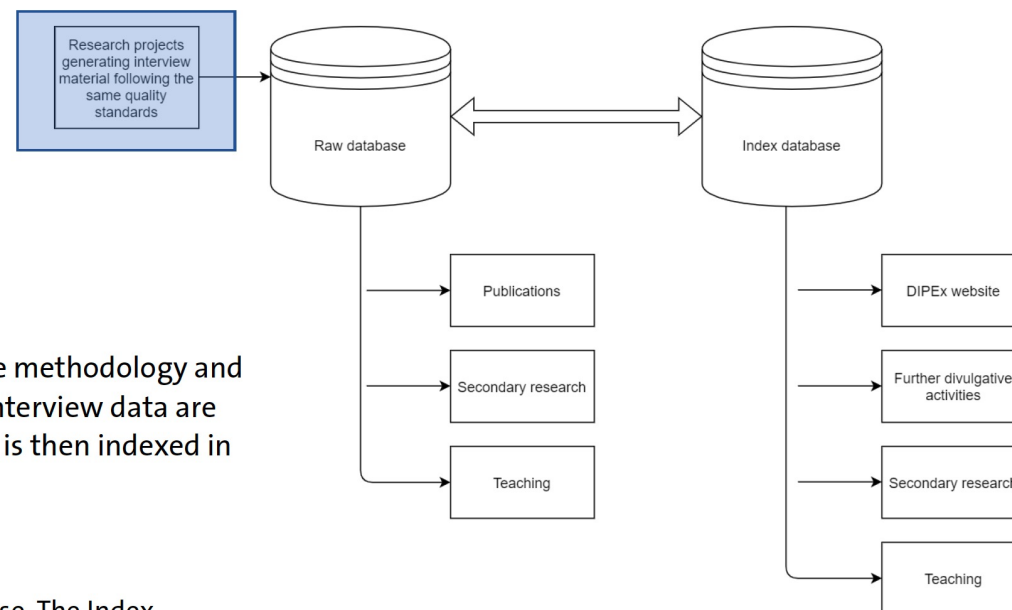
*Context: Alzheimer patient reporting on coping mechanisms*

“If I was alone at home, I think I would decompensate. I would not like that at all. Like I already said, I am often losing things. And I do not want to cook. But I like to help, I help my daughter and my grandchildren, they want me to be well. I always laugh, because I have a drawer in my room, a secret drawer. Then the grandchildren come and say: ‘Please, don’t tell mom, but are there still any sweets or chocolate or chewing gum in there?’ <<<chuckles>>>, the little ones help me to get over it. Yes, I think it would not be good if I was alone.”

*(Translation NBA)*



## Data flow



### Data in:

Interview data generated with the same methodology and with the same quality standards. Raw interview data are stored in the raw dataset. Their content is then indexed in the index database.

### Data out:

Data can be explored via the Index database. The Index database contains the metadata of the Raw database, but also organized sections from the same data. Depending on the purpose, secondary research or teaching activities can use data from the Index dataset or from the Raw dataset.





## Output formats

DIPEX.ch website

Publications

Event series „Patienten erzählen“ (“Patients tell their story“)

Trigger movies

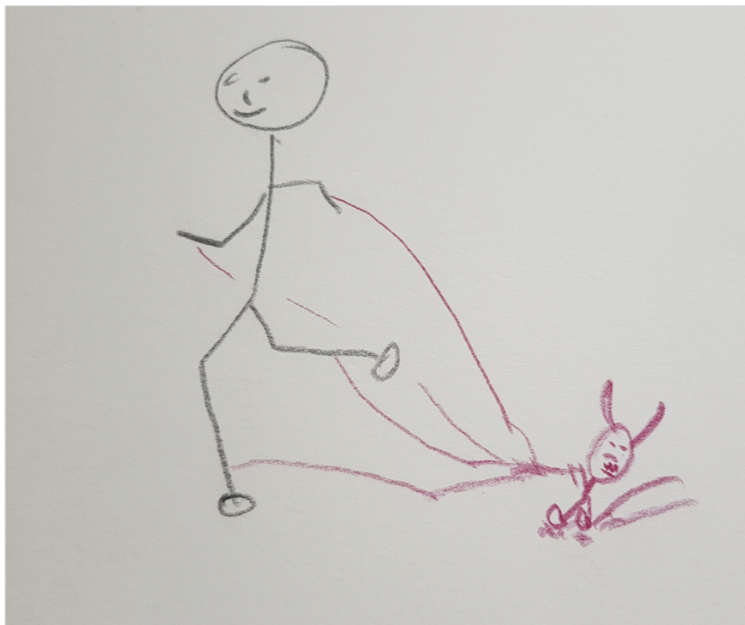
Instagram posts

...



<https://dipex.ch/illness/multiple-sclerosis/>

## Beyond text, audio or video clips



A patient's experience with Deep Brain Stimulation



## THE PERSISTENCE OF MEMORY – DEMENTIA AND DIGITAL AID TOOLS FOR DECISION-MAKING

In the context of the artists-in-labs residencies “The Persistence of Memory”, artists have explored a broad range of topics related to dementia. They exchanged and shared experiences, expertise and ideas with researchers, medical professionals as well as dementia patients and developed artistic projects.

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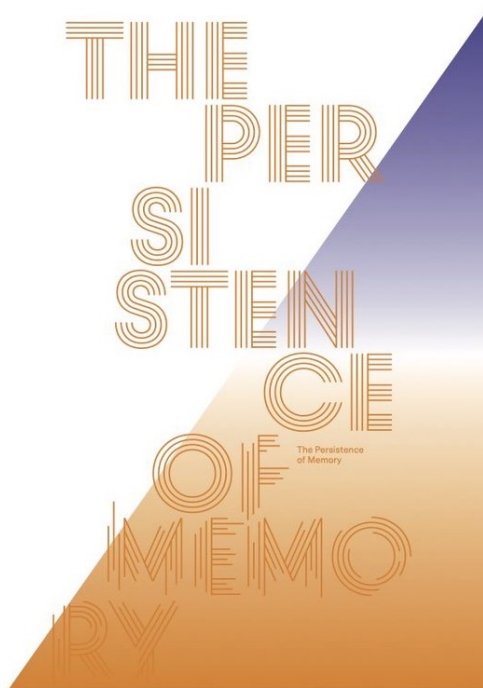
hdk

Zürcher Hochschule der Künste  
Zürich University of the Arts

Forschungsprojekte

DE

## AIL – artists-in-labs program



📍 Zürich, 18. November 2021

📷 f 🐦

TICKET-INFO

0 days 0 hrs 0 min

HOME PROGRAMM ▾ GALERIE ▾ NEWS ▾ ÜBER UNS ▾ UNTERSTÜTZER ▾ PROGRAMM APPETIZER



### Schmerz hat viele Gesichter – Kunst, Medizin und Philosophie im Dialog

Performative Lesung & Podiumsdiskussion – Organisiert von artists-in-labs program (ZHdK), Institut für Biomedizinische Ethik und Medizingeschichte IBME (Universität Zürich), Zentrum für Schmerzmedizin Nottwil (Schweizer Paraplegiker-Zentrum), Alte Anatomie - Forum für Medizin & Gesellschaft



## Example ICU

Funding for research project with specific question (perception of coercion)

Two (intensive care) physicians who had received additional methods training

Cooperation with nursing scientists from ZHAW (Maria Schubert, Olivia Blumenfeld)

Scoping review of qualitative literature > confirm gap of qualitative studies of patient perspective on ICU as coercive setting

Conceptual analysis > understanding of coercion, broaden scope

Paper presenting empirical data

DIPEX module

Collaboration with Swiss Intensive Care Society: add health professional perspective, create educational materials (trigger films)





## Additional projects

1. Exploring quantitative evidence for value of patient narratives:

Drewniak D et al. *Risks and Benefits of Web-Based Patient Narratives: Systematic Review*. [J Med Internet Res](#). 2020 Mar; 22(3): e15772.

2. Use of DIPEX material for teaching and exams:

Glässel A et al. *Real patient experiences meet simulation patients for OSCE: Workshop experiences from interprofessional education*. *GMS J Med Educ* 2021;38(5):Doc91.

3. «With us about us»: *Patient narratives as co-production*. Project funded by the Participatory Science Academy (Seiler K, Schwind B et al.)

4. Position paper: *Good practice standards for patient experience reports* (DNGK/German Network for Health Literacy, in development)

5. Computer linguistic analyses of DIPEX (with G Schneider, T Ellendorff, D Ettlin), project in development with Digital Society Initiative UZH and Language & Medicine Center UZH



## Added value: not just „stories“

- Harness the **power of patient voices** to stimulate improvement of the health care system (e.g. patient-centeredness, inefficiencies)
- Remedy **lack of patient representation** through a systematic collection of (narrative) evidence
- Improve **access** to, interdisciplinary **use** and **impact** of research results
- Allow for **patient/citizen participation** (“citizen science”, experience-based co-design)
- Opportunity for **interdisciplinary collaboration** (with other health professionals, with arts and design, Medical Humanities)
- Create attractive (interprofessional) **teaching materials**, low threshold exposure to patient experience > complementing bedside teaching



## Does hearing the patient perspective improve consultation skills in examinations? An exploratory randomized controlled trial in medical undergraduate education

Rosamund Snow<sup>a</sup> , Joanna Crocker<sup>a,b</sup> , Katherine Talbot<sup>c</sup>, Jane Moore<sup>c</sup> and Helen Salisbury<sup>a</sup>

<sup>a</sup>Health Experiences Institute, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK; <sup>b</sup>NIHR Oxford Biomedical Research Centre, Oxford, UK; <sup>c</sup>Nuffield Department of Obstetrics & Gynaecology, University of Oxford, Oxford, UK

### ABSTRACT

**Purpose:** Medical education increasingly includes patient perspectives, but few studies look at the impact on students' proficiency in standard examinations. We explored students' exam performance after viewing video of patients' experiences.

**Methods:** Eighty-eight medical students were randomized to one of two e-learning modules. The experimental group saw video clips of patients describing their colposcopy, while the control group viewed a clinician describing the procedure. Students then completed a Multiple Choice Questionnaire (MCQ) and were assessed by a blinded clinical examiner in an Objective Structured Clinical Examination (OSCE) with a blinded simulated patient (SP). The SP scored students using the Doctors' Interpersonal Skills Questionnaire (DISQ). Students rated the module's effect on their skills and confidence. Regression analyses were used to compare the effect of the two modules on these outcomes, adjusting for gender and graduate entry.

**Results:** The experimental group performed better in the OSCE than the control group (odds ratio 2.7 [95%CI 1.2–6.1];  $p=0.016$ ). They also reported significantly more confidence in key areas, including comfort with patients' emotions (odds ratio 6.4 [95%CI 2.7–14.9];  $p<0.0005$ ). There were no other significant differences.

**Conclusion:** Teaching that included recorded elements of real patient experience significantly improved students' examination performance and confidence.





## “Robust national studies with narrative interviews”

- Database for research
- Website as resource for patients
- Material for (continued) medical/health professional education
- Insights and impulses for health care improvement
- Inform development of PROMs, decision aids, informed consent forms...
- Complement disease registries and other quantitative data collections





## The New York Times

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### **TheUpshot**

#### THE NEW HEALTH CARE

## *Sometimes Patients Simply Need Other Patients*

Using the internet for a diagnosis is not recommended, but there's great power in sharing stories.

<https://www.nytimes.com/2018/07/09/upshot/sometimes-patients-simply-need-other-patients.html>



## Why DIPEX.ch?



### The Lancet Global Health Commission

## High-quality health systems in the Sustainable Development Goals era: time for a revolution

Margaret E Kruk, Anna D Gage, Catherine Arseneault, Keely Jordan, Hannah H Leslie, Sanam Roder-DeWan, Olusoji Adeyi, Pierre Barker, Bernadette Daelmans, Svetlana V Doubova, Mike English, Ezequiel García Elorrio, Frederico Guanais, Oye Gureje, Lisa R Hirschhorn, Lixin Jiang, Edward Kelley, Ephrem Tekle Lemango, Jerker Liljestrand, Address Malata, Tanya Marchant, Malebona Precious Matsoso, John G Meara, Manoj Mohanan, Youssoupha Ndiaye, Ole F Norheim, K Srinath Reddy, Alexander K Rowe, Joshua A Salomon, Gagan Thapa, Nana A Y Twum-Danso, Muhammad Pate



### Panel 2: Beyond the numbers—experiences in the health system\*

Interviews with patients help to paint a more comprehensive picture of their experiences within the health system. The Word Bank's landmark publication, *Voices of the Poor*,<sup>41</sup> in 2000 shared the narratives of individuals across the world and described the challenges that the poor face in not only accessing health care but also successfully navigating the health system. Since then, several qualitative studies have further illuminated the ways in which people receive differential treatment while seeking care. We did a rapid review of these studies (methods are described in appendix 1). The stories described in these studies highlight disparities in both competent care and user experience.

SOUNDING BOARD

## Taking Patients' Narratives about Clinicians from Anecdote to Science

Mark Schlesinger, Ph.D., Rachel Grob, Ph.D., Dale Shaller, M.P.A., Steven C. Martino, Ph.D.,  
Andrew M. Parker, Ph.D., Melissa L. Finucane, Ph.D., Jennifer L. Cerully, Ph.D.,  
and Lise Rybowski, M.B.A.

N ENGL J MED 373;7 NEJM.ORG AUGUST 13, 2015

# Narrative vs Evidence-Based Medicine— And, Not Or

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Zachary F. Meisel, MD, MPH, MS

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Jason Karlawish, MD

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**T**HE WEEK BEFORE THE US PREVENTIVE SERVICES TASK Force (USPSTF) released its recommendations against routine prostate screening for healthy men, celebrity patients including Joe Torre and Rudy Giu-

includes information about scene, characters, and conflict and raises questions and provides resolution.<sup>4</sup> From this framework, stories that link individuals and their experiences to evidence are tools to translate (not drive) science without introducing anecdotal bias.

Scientists can use narrative in at least 2 ways. First is in the form of counternarratives, designed to neutralize stories that promote disproven theories. Take the largely ne-



## Challenges and opportunities

Resource intensity:

- Recruitment, consenting, interviewing
- Transcription and coding
- Multilingual platform
  - Digitalization/AI (Autorecording, semi-automated coding, speech-to-text programs, DeepL etc.)

Funding: Limited resources for qualitative research

- Show impact/effectiveness of narratives in a quantitative paradigm
- Secure core funding
- Create synergies through collaborations

Abundance of “stories” in the internet/on social media

- Reaching target audiences
- Communicating USP
  - Professional dissemination strategy



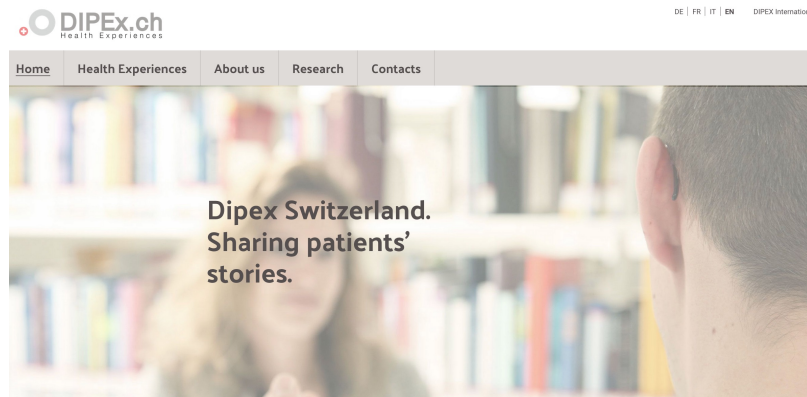
## Next steps

- Found a „Förderverein“ (supporting organization)
- Develop courses/thesis opportunities for medical students and other health professionals that draw on/co-develop DIPEX material
- Design and roll out dissemination strategy in collaboration with ZHdK
- Explore joint database structure at DIPEX International Meeting in 2022
- Contribute to mainstreaming narrative elements in medical research and publications
- Build strong network of collaborators (UZH, CH hospitals, DI)





**Thanks for your attention  
and interest**



**Questions and  
comments welcome**

**... And a big thank you to a  
wonderful team:**

Dominik Bolliger (IT)  
Yolanda Chacon (Law)  
Dr Daniel Drewniak (Sociology)  
Dr Margrit Fässler (Medicine)  
Dr Andrea Glässel (Public Health)  
Dr Manya Hendricks (Anthropology)  
Dr Martina Hodel (Psychology)  
Dr Susanne Joebges (Medicine)  
Silvia Lazzarotto (Medicine)  
Dr Corine Mouton Dorey (Medicine)  
Andrea Radvanszky (Sociology)  
Tania Manriquez Roa (Anthropology)  
Dr Bettina Schwind (Sociology/Gender studies)  
Karin Seiler (Design)  
Giovanni Spitale (Philosophy)  
Mirriam Tyebally Fang (Medicine)  
Sebastian Wäscher (Sociology)  
Dr Kristina Würth (Anthropology)







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## Outlook



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## Excellence in Patient Care Symposium 2021

The Swiss Database of Individual Patient  
Experiences (DIPEX.ch)





## dipex.ch Dissemination Instagram Concept

### Goals

- Present DIPEX modules.
- Bring users to the DIPEX-website.
- Communicate events/ news.

### Modules

- Each module is represented through a series of 3- 5 posts that highlight relevant topics.

### Topics

- are highlighted through a post with a slide sequence of 3 - 5 images combined with quotes.

Typographic posts



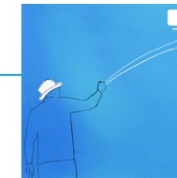
Portrait

### Visual identity

- is defined by a selection of conceptual design elements such as illustrations, quotes, questions, portraits etc.

### Storytelling

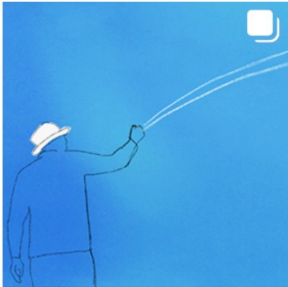

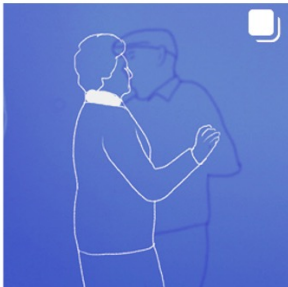
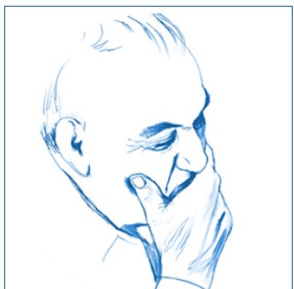
- is based on quotes from the DIPEX interviews and sequential images.



Teaser image

## Instagram Visual Elements

Dementia module prototypes.

	Illustrations/ Visual stories	Quotes from interviews	Statements/questions	Portraits
Topic: Caregivers' perspective		<p>“ Als Angehöriger hat man ein Mit- spracherecht.</p> <p>Setzt euch dafür ein!</p>	<p>“</p> <p>Was ist gute Demenzpflege?</p>	
Topic: Staying active		<p>“ Pour faire travailler le cerveau il faut s'occuper.</p>	<p>“</p> <p>Mit Demenz leben lernen.</p>	





## Instagram Post Elements

### Storytelling (swiping)



## Storytelling

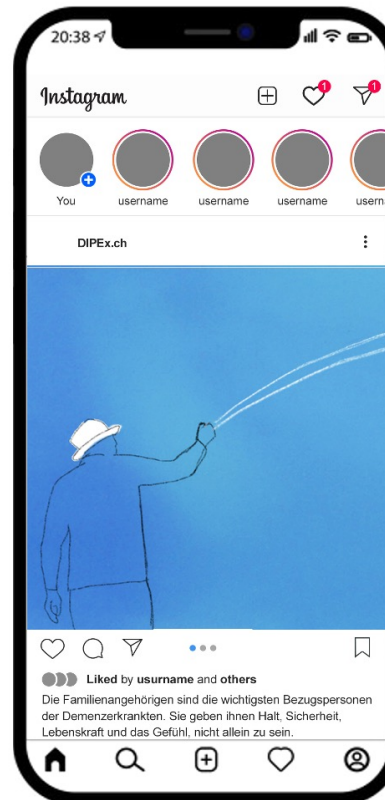
### Storytelling (swiping)

Series of 3 - 5 images.  
representing a certain topic.  
Sample: Staying active.

### Key findings in text

*„The family members are the most important caregivers of the of dementia patients. They give them support, security, vitality and the feeling that they are not alone. Dementia patients are existentially dependent. The relatives experience that those close to them become helpless. Dementia is a biographical turning point not only for the person with dementia, but also for the relatives.*

1 Key visual/ teaser

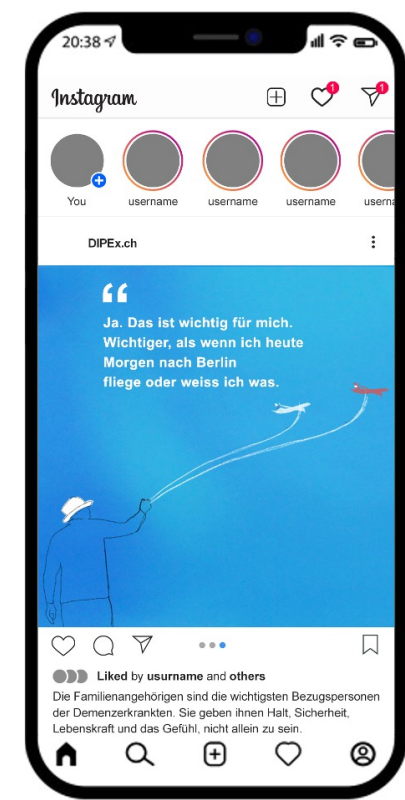


2 Quote part 1



*„For me now the meaning of life is to be grateful for a life that I had and still have still have and at the same time to show thankfulness to my mother, who depends on me.*

3 Quote part 2



*Yes, that is important for me. More important than to be able to go to fly to Berlin tomorrow or whatever.“*

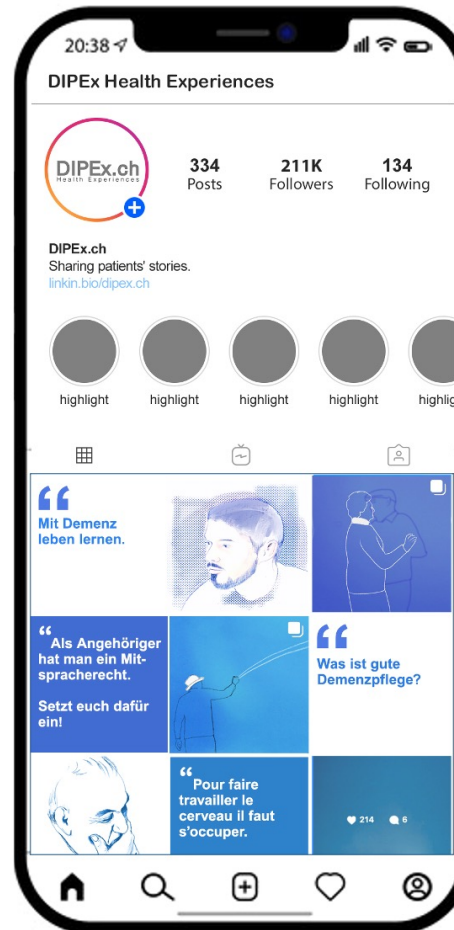


## Instagram Feed

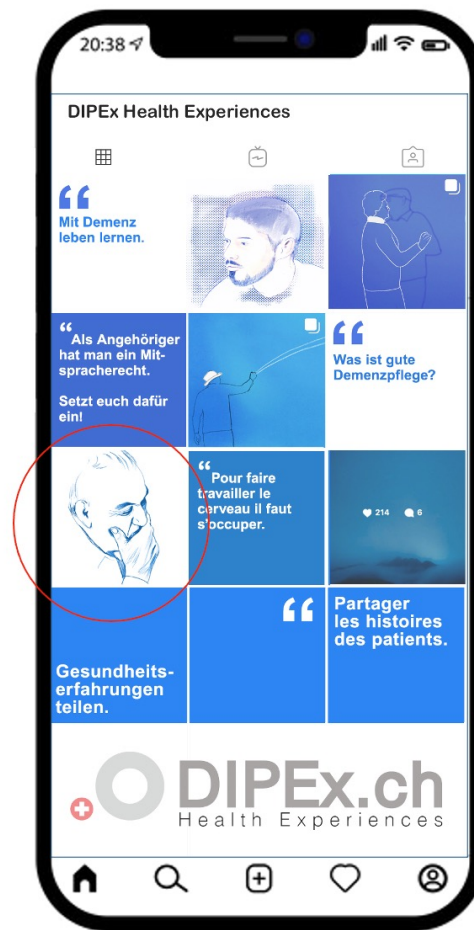
### Mobile Mockup

- Online as of Nov 26th - if you want to follow ...!
- Establishing name, logo mission statement and languages
- Active posting will start in January 2022
- Varying visual elements and topics
- Posting events/ new modules etc.

Feed with profile



Scrolling the feed





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<https://www.ibme.uzh.ch/en/Biomedical-Ethics/Agenda/Previous-Events/EPC-Symposium2021.html>



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