Data sharing is the future.

With a FAIR database of individual patient experiences

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1. Do we need a shared data structure?
2. Understand the structure and properties of our data
3. Detail our data infrastructure
4. Present our in/out data flows
5. Discuss about future possibilities

Do we need a shared data structure?

Proposal (from June 2021) :

Open a discourse on the data access model, keeping in mind cost of the data collection, possible exploits for commercial purposes, and infrastructure;

Start to reason on the feasibility of an international "meta-database", i.e: a harmonized catalogue of existing datasets and a set of rules for developing new datasets;

Reflect on the criteria for retrospective harmonization;

Leverage on existing experience - from the COVID study but also from other fields, e.g the Maelstrom catalogue (epidemiology)
https://www.maelstrom-research.org/page/publications

1. A shared data structure

It makes sense if:
- We want to increase interoperability, data exchange, data pooling and collaborations;
- We want to foster secondary research, teaching, and education;
- We want to probe new dissemination strategies;
- We want to set common quality standards;
- We want to reduce development and maintenance costs.
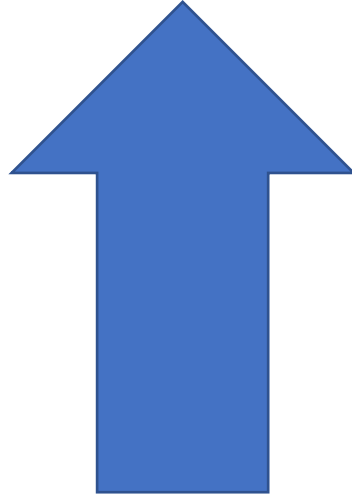
It does not make sense if:
- We are jealous;
- We are shy;
- Other reasons I cannot think of.

1. A shared data structure

It requires harmony:
- Data are generated in the same way;
- Data have the same shape;
- Data have the same classification properties;
- Data are pulled for similar purposes.

That's what I see in my wildest dreams

OPEN question 1:

Do we want to increase interoperability, data exchange, data pooling and collaborations; foster secondary research, teaching, and education; probe new dissemination strategies; set common quality standards; and reduce development and maintenance costs?

OPEN question 2:

Are our data harmonic? Are they generated in the same way, with the same shape, with the same classification properties?

Do we use them for similar purposes?

Our data

2. Our data

Individual Patient Experiences
Subjective narratives in which
participants tell their own
experience from their own point of
view

Database
Data are indexed and structured,
accessible to multiple actors for
different purposes

Local branch
One among many!

DIPEx.ch
Gesundheitserfahrungen
Expériences de Santé
Esperienze di Salute
Health Experiences

2. Our data

DIPEx International is a network comprising research groups from 14 countries.

We all follow the same methodology and generate similar data.

1. Our data

Interview guide
Semi-structured document listing the questions to ask and the prompts to give to the interviewee. Starts with an open section then follows specific topics of interest.

Interview files
The interview is audio and/or video recorded – according to the preferences of the itwee – and then transcribed as text.
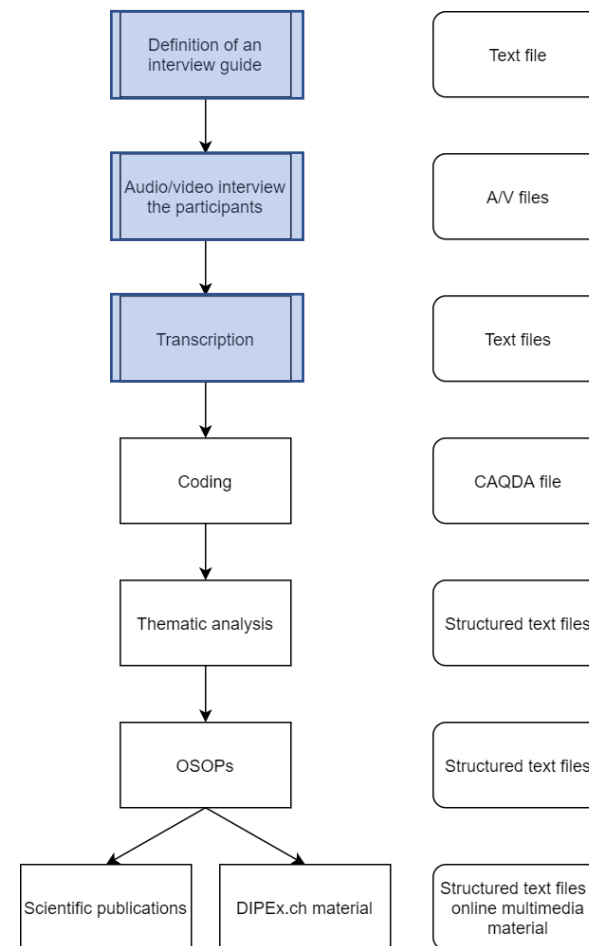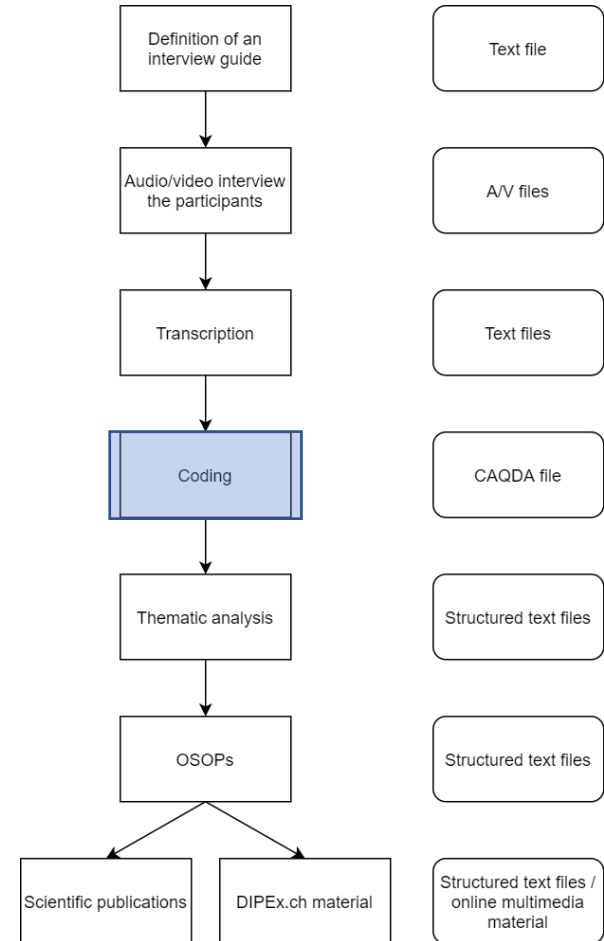
2. Our data

Coding
The interviews are loaded in a software for computer assisted qualitative data analysis. We define a specific coding tree and manually code the text (= assing one or more labels to a meaningful passage)
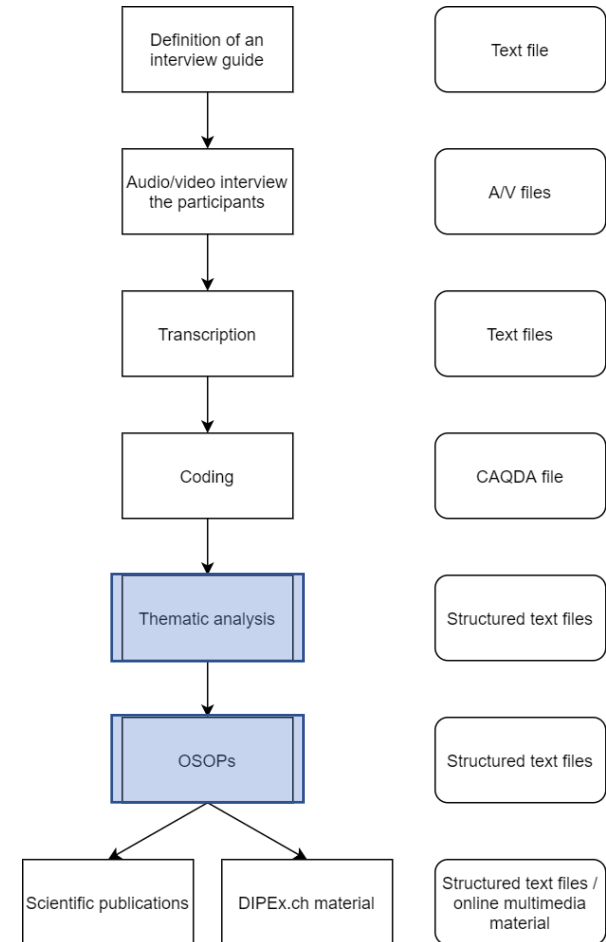
| Definition of an interview guide	Text file
Audio/video interview the participants	A/V files
Transcription	Text files
Coding	CAQDA file
Thematic analysis	Structured text files
OSOPs	Structured text files
Scientific publications / DIPEx.ch material	Structured text files / online multimedia material

2. Our data

Thematic analysis and OSOPs
We select specific topics that allow us to tell the 'collective history' of a given experience weaving individual voices together. We attribute codes to topics, retrieve the quotes, and put the story together.

Process	Output
Definition of an interview guide	Text file
Audio/video interview the participants	A/V files
Transcription	Text files
Coding	CAQDA file
Thematic analysis	Structured text files
OSOPs	Structured text files
Scientific publications / DIPEx.ch material	Structured text files / online multimedia material

2. Our data

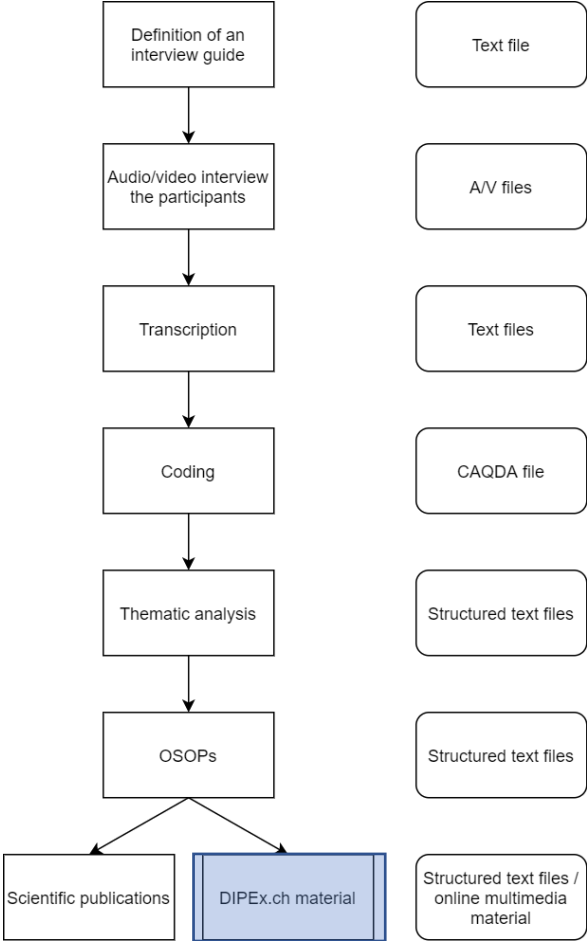| Year/Publication	Language
2020	
Duff, C., Kokanović, R., Flore, J., Thomas, SDM., Callard, F. & Blackman, L. (2020). Perspectives on person-centred care for borderline personality disorder: A critical research agenda. Health Sociology Review, 29(1), 1-15. https://doi.org/10.1080/14461242.2020.1715815 ⊙	English
Davies, L., LeClair, K. L., Bagley, P., Blunt, H., Hinton, L., Ryan, S., & Ziebland, S. (2020). Face-to-Face Compared With Online Collected Accounts of Health and Illness Experiences: A Scoping Review. Qualitative Health Research, 30(13), 2092–2102. https://doi.org/10.1177/1049732320935835 ⊙	English
Flore, J., Kokanović, R., Duff, C. & Callard, F. (2020). The antidepressant in women's lifeworlds: Feminist materialist encounters. BioSocieties. https://doi.org/10.1057/s41292-020-00189-2 ⊙	English
Ghio, D., Muller, I., Greenwell, K., Roberts, A., McNiven, A., Langan, S.M. & Santer, M., 2020. 'It's like the bad guy in a movie who just doesn't die': A qualitative exploration of young people's adaptation to eczema and implications for self-care. British Journal of Dermatology, 182(1), 112-118. https://doi.org/10.1111/bjd.18046 ⊙	English
Holmberg, C. & Breuning, M. (in print). Personal Experiences of Illness. In S. Scrimshaw, S. Lane, R, Rubenstein & J. Fisher (Eds.), The SAGE Handbook of Social Studies in Health and Medicine (2nd ed.). Sage.	English
Johnston-Ataata, K., Flore, J., Kokanović, R., Hickey, M., Teede, H., Boyle, J. & Vincent, A. (2020). 'My relationships have changed because I've changed': Biographical disruption, personal relationships, and the formation of an early menopausal subjectivity. Sociology of Health and Illness, 42(7), 1516-1531. https://doi.org/10.1111/1467-9566.13143 ⊙	English
Locock, L., Graham, C., King, J., Parkin, S., Chisholm, A., Montgomery, C., Gibbons, E., Ainley, E., Bostock, J., Gager, M., Churchill, N,, Dopson, S., Greenhalgh, T., Martin, A., Powell, J., Sizmur, S. & Ziebland, S. (2020) Understanding how front-line staff use patient experience data for service improvement: An exploratory case study evaluation. Health Services and Delivery Research, 8(13). https://doi.org/10.3310/hsdr08130 ⊙	English
Locock, L., Montgomery, C., Parkin, S., Chisholm, A., Bostock, J., Dopson, S., Gager, M., Gibbons, E., Graham, C., King, J., Martin, A., Powell, J., & Ziebland, S. (2020). How do frontline staff use patient experience data for service improvement? Findings from an ethnographic case study evaluation. Journal of Health Services Research & Policy, 25(3), 151–161. https://doi.org/10.1177/1355819619888675 ⊙	English
O'Brien, N., Law, S., Proulx-Boucher, K., Menard, B., Skerritt, L., Boucoiran, I., Cox, J., Andersson, N. & de Pokomandy, A. (2020). Co-designing care improvements for women living with HIV: A patient-oriented deliberative dialogue workshop in Montréal, Québec. CMAJ Open, 8(2) E264-E272. https://doi.org/10.9778/cmajo.20190158 ⊙ *	English
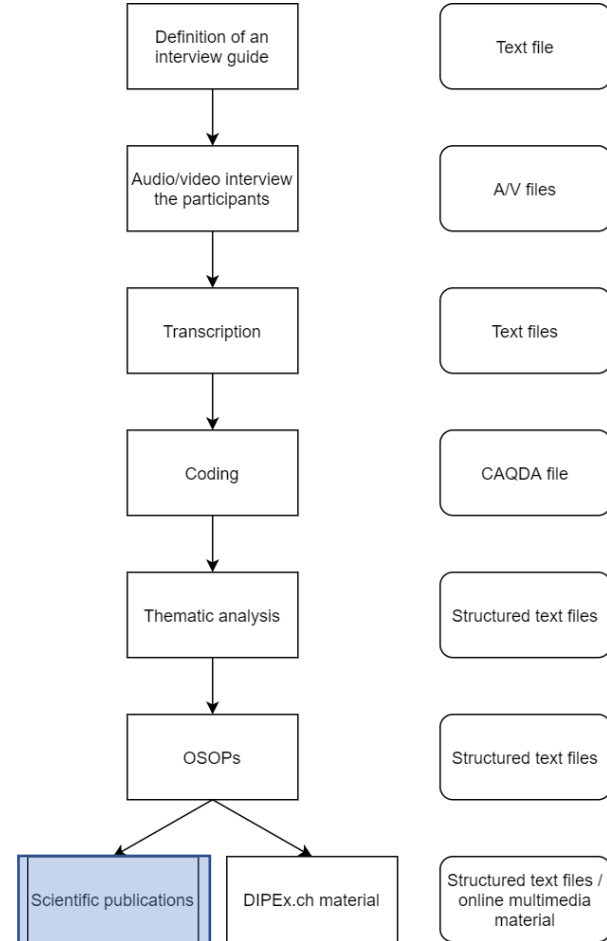
2. Our data

Website material
Based on the OSOPs, we prepare selected material to be put online and serve as an important resource for patients, relatives, caregivers, healthcare professionals, and students.
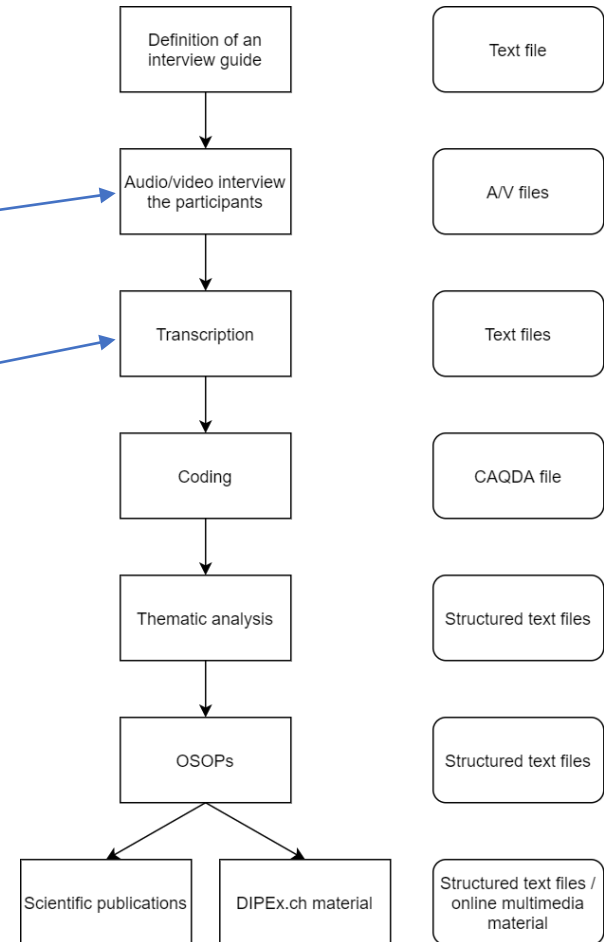
Process	File type
Definition of an interview guide	Text file
Audio/video interview the participants	A/V files
Transcription	Text files
Coding	CAQDA file
Thematic analysis	Structured text files
OSOPs	Structured text files
Scientific publications / DIPEx.ch material	Structured text files / online multimedia material

2. Our data

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)

Process	Output
Definition of an interview guide	Text file
Audio/video interview the participants	A/V files
Transcription	Text files
Coding	CAQDA file
Thematic analysis	Structured text files
OSOPs	Structured text files
Scientific publications / DIPEx.ch material	Structured text files / online multimedia material

Key message 1

We collect semi-structured interviews of people telling their own experience with selected health conditions. We transcribe and code the interviews, conduct thematic analysis and use the resulting material for publications and divulgation.

Our data are generated in the same way, hence have the same ontological properties.

Our data are analyzed in the same way, hence have the same classification (=relational) properties.
Each experience belongs to a topic, which belongs to a category, which belongs to a module.
Each experience belongs to one interviewee.

3. Data structure and infrastructure

This is how we (CH) do it

There might be other ways for sure. This is ours, and my guess is that it's gonna be similar to yours.

The point is: if the structure is similar, we might meet the 'harmony' criteria detailed above.

3. Data structure and infrastructure

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
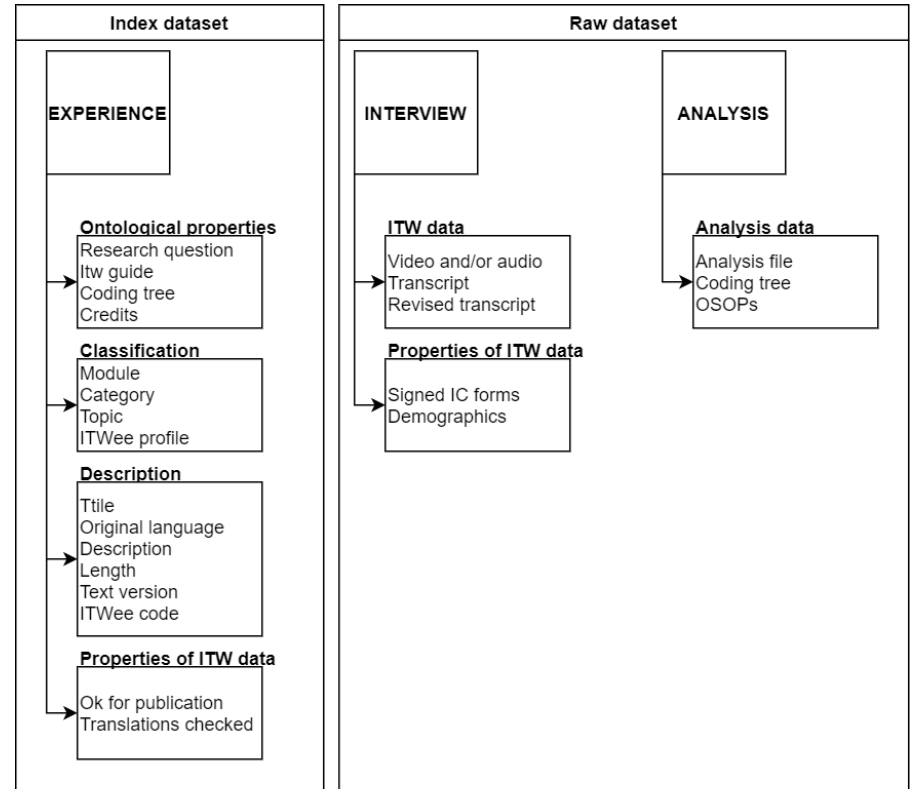
3. Data structure and infrastructure

Interviews
Material resulting from the interview: original audio / video; transcript; revised transcript; informed consents; demographic variables of the interviewee

Analysis
Analysis material regarding all the interviews: CAQDA master file, coding tree, OSOPs
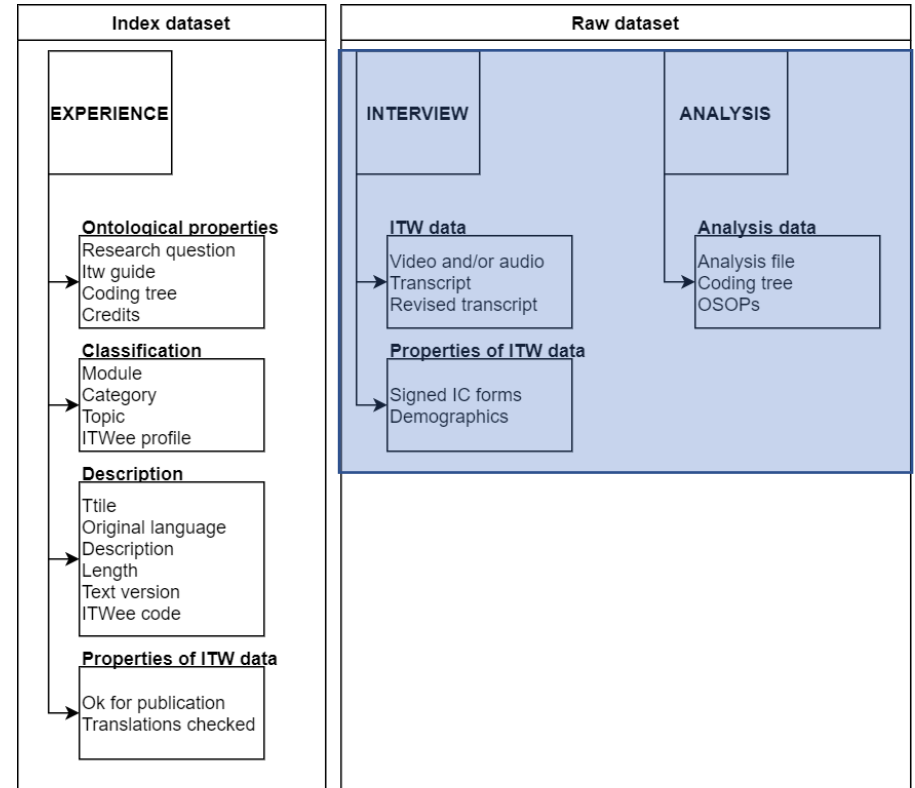
3. Data structure and infrastructure

Experience
Minimal viable entity of the dataframe, defined as one narrative block with thematic coherence.

Each experience has ontological properties (= how it was generated/extracted); classification properties (=triple set module/category/topic); descriptive properties; data management properties.
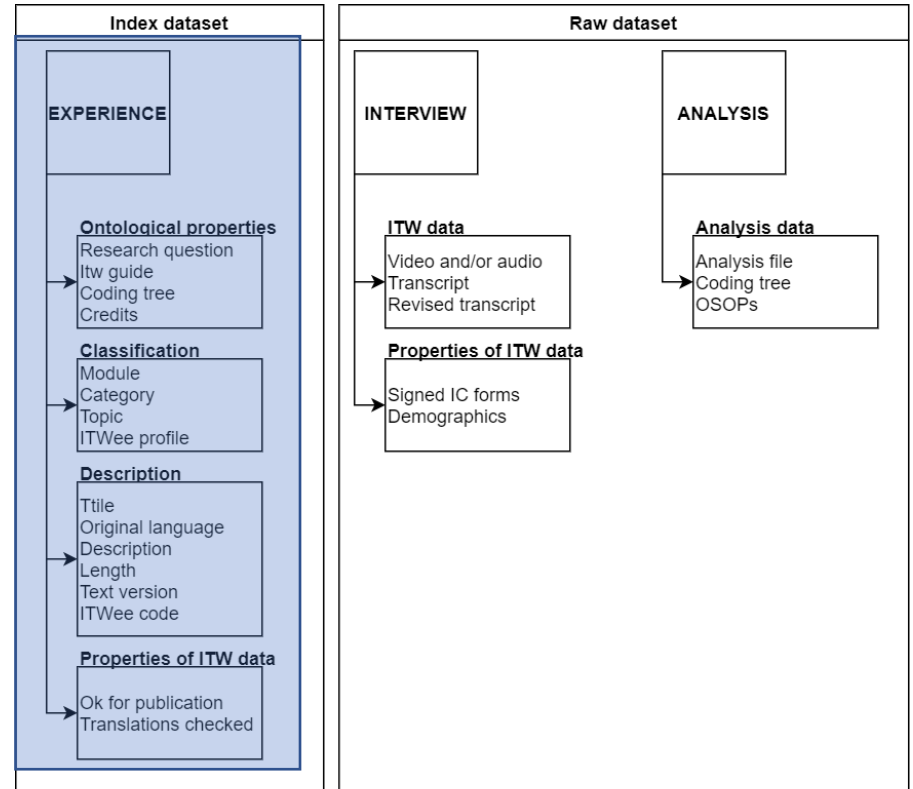
3. Data structure and infrastructure

Title
Giovanni explains why he tinks index databases are
a cool idea
Description
…
Belongs to module
DBS
Interviewee code
DBS01
Original language
ENG
Start time
00:15:01
End time
00:20:08
Belongs to category
Data infrastructure
Belongs to topic
Granular organization of the data

The stuff I was saying one slide ago
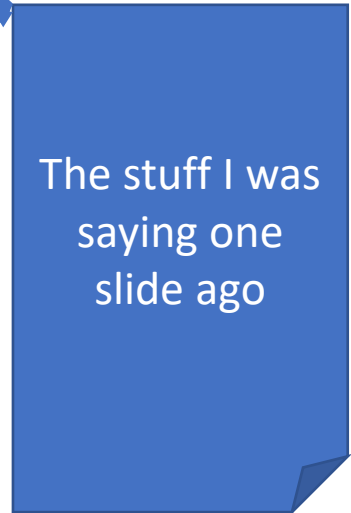
Video and/or audio and/or text

3. Data structure and infrastructure

#	Nome	Tipo di dati	Lunghezza/set	Senza s...	Permetti ...	Riem...	Predefinito	Commento	Confronto	Espressione	Virtualità
1	**ID_Experience**	**INT**	**11**	☐	☐	☐	**AUTO_INCREME...**				
2	Belongs_to_module	VARCHAR	3	☐	☑	☐	Nessun valore pr...				
3	ITW_code	VARCHAR	100	☐	☑	☐	Nessun valore pr...				
4	ITWee_code	VARCHAR	5	☐	☑	☐	Nessun valore pr...				
5	ITW_original_langu...	VARCHAR	3	☐	☑	☐	Nessun valore pr...				
6	EXP_start_time	TIME		☐	☑	☐	Nessun valore pr...				
7	EXP_end_time	TIME		☐	☑	☐	Nessun valore pr...				
8	EXP_duration	TIME		☐	☑	☐	Nessun valore pr...			timediff(`EXP_...	STORED
9	EXP_video_link	VARCHAR	255	☐	☐	☐	Nessun valore pr...				
10	EXP_thumbnail	VARCHAR	255	☐	☑	☐	NULL				
11	EXP_category	VARCHAR	500	☐	☑	☐	Nessun valore pr...				
12	EXP_topic	VARCHAR	1000	☐	☑	☐	Nessun valore pr...				
13	EXP_name_ENG	VARCHAR	500	☐	☑	☐	NULL				
14	EXP_name_DEU	VARCHAR	500	☐	☑	☐	NULL				
15	EXP_name_FRE	VARCHAR	500	☐	☑	☐	NULL				
16	EXP_name_ITA	VARCHAR	500	☐	☑	☐	NULL				
17	EXP_description_ENG	TEXT		☐	☑	☐	NULL				
18	EXP_description_DEU	TEXT		☐	☑	☐	NULL				
19	EXP_description_FRE	TEXT		☐	☑	☐	NULL				
20	EXP_description_ITA	TEXT		☐	☑	☐	NULL				
21	EXP_textversion_ENG	TEXT		☐	☑	☐	NULL				
22	EXP_textversion_DEU	TEXT		☐	☑	☐	NULL				
23	EXP_textversion_FRE	TEXT		☐	☑	☐	NULL				
24	EXP_textversion_ITA	TEXT		☐	☑	☐	NULL				
25	Translation_OK	TINYINT	1	☐	☑	☐	NULL				
26	Publication_OK	TINYINT	1	☐	☑	☐	Nessun valore pr...				

3. Data structure and infrastructure

3. Data structure and infrastructure

Findable
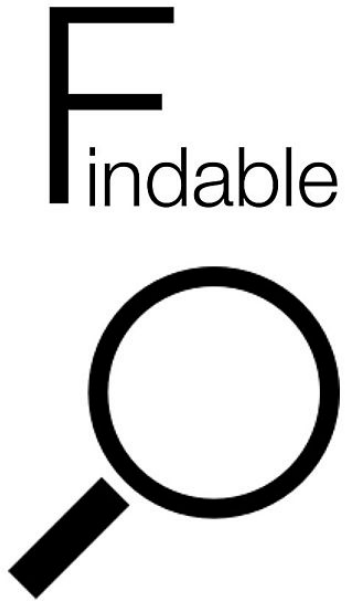
Findable data
Everyone (people and machines) with access to the database can navigate the metadata; can know what data we have; can search them using any of the fields building complex queries.

3. Data structure and infrastructure

Accessible

Accessible data
The communication protocol is free and open; it allows (different levels of) authentication and authorization; the metadata are always available.

3. Data structure and infrastructure

Interoperable data
Data use open formats (as much as possible) = shared language for knowledge representation; data include references and pointers = from where the data come from, where the data are used.

Interoperable
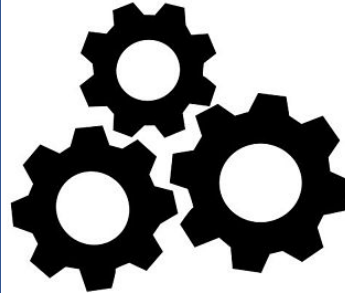
3. Data structure and infrastructure

Reusable data
The ultimate goal of FAIR is to optimise the reuse of data. Metadata and data are well-described so that they can be replicated and/or combined in different settings (by people and machines).

Reusable
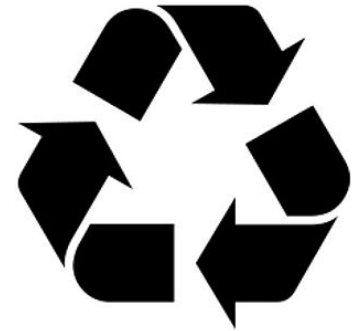
Key message 2

We store data and metadata under FAIR principles, building a future-proof data infrastructure which allows people and machines to access the data.

4. Data flow

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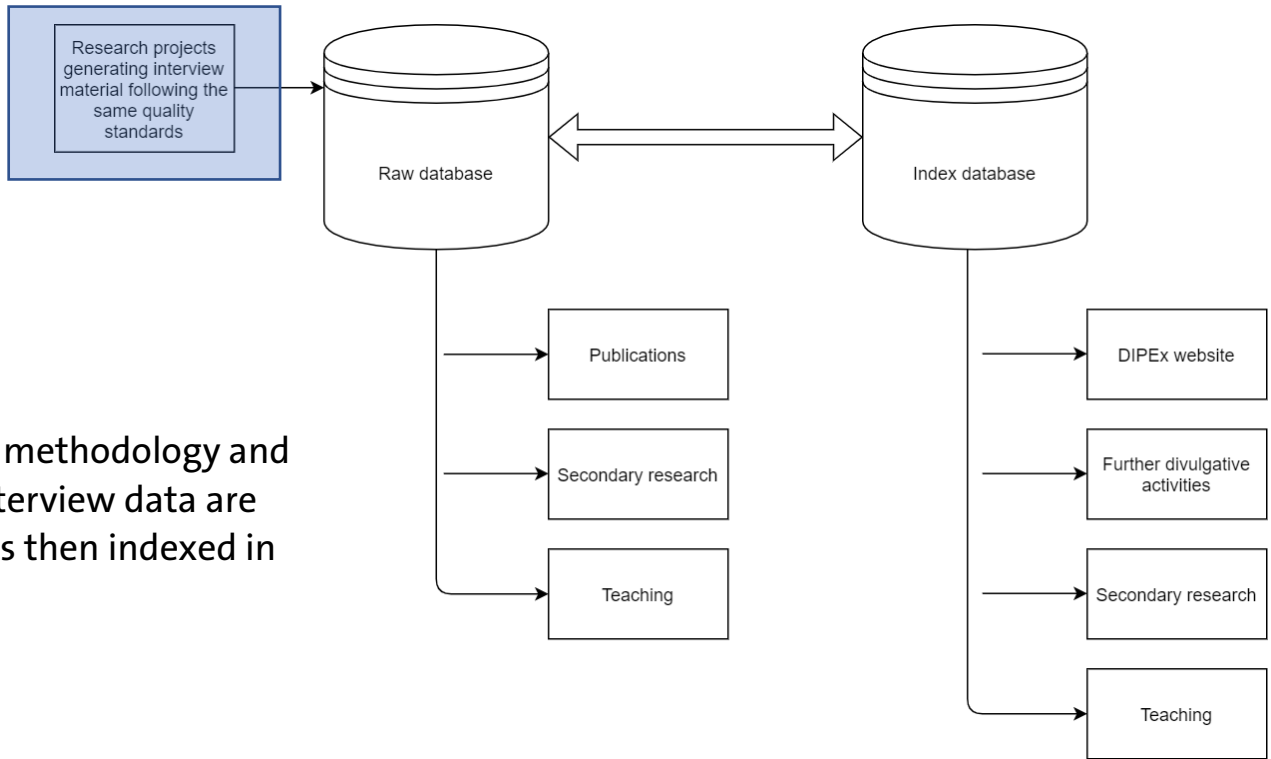
Data in:
Interview data generated with the same methodology and with the same quality standards. Raw interview data are stored in the raw dataset. Their content is then indexed in the index database.

Research projects generating interview material following the same quality standards

Raw database

Index database

Publications

Secondary research

Teaching

DIPEx website

Further divulgative activities

Secondary research

Teaching

4. Data flow

DIPEx.ch
Gesundheitserfahrungen
Expériences de Santé
Esperienze di Salute
Health Experiences

EXPERIENCES

ID_Experience

`13`

Belongs to Module
`CMI` ▼

Belongs to Category
`General perception / overview of the intensive care` ▼

Belongs to Topic
`DEEPL: The general perception that the patients ha` ▼

[New Experience]

[Select module]

This table lists all the available combinations of categories and topics for the selected module.

It does not allow editing. If you want to modify a category or a topic, please use the appropriate form.

Please consult it before filling in the related fields in the drop-down menus on the left←

Module	Category	Topic
CMI	Communication	ways to communicate
CMI	Communication in the ICU	trust and safety
CMI	Communication in the ICU	Team and family support
CMI	Communication in the ICU	Willingness and time to communic
CMI	Communication in the ICU	possibilities of misunderstanding
CMI	Communication in the ICU	DEEPL: The general perception that
CMI	General perception / overview of the i	DEEPL Environmental perception.
CMI	General perception / overview of the i	DEEPL General perception of relativ
CMI	State of consciousness and memory is	DEEPL Forgetting / remembering w
CMI	State of consciousness and memory is	Delusion/hallucination/ dreams/ Fe
CMI	State of consciousness and memory is	DEEPL Waking up in ICU
CMI	State of consciousness and memory is	Coma/Sedation

INTERVIEWEE

Interviewee Code
▼

4. Data flow
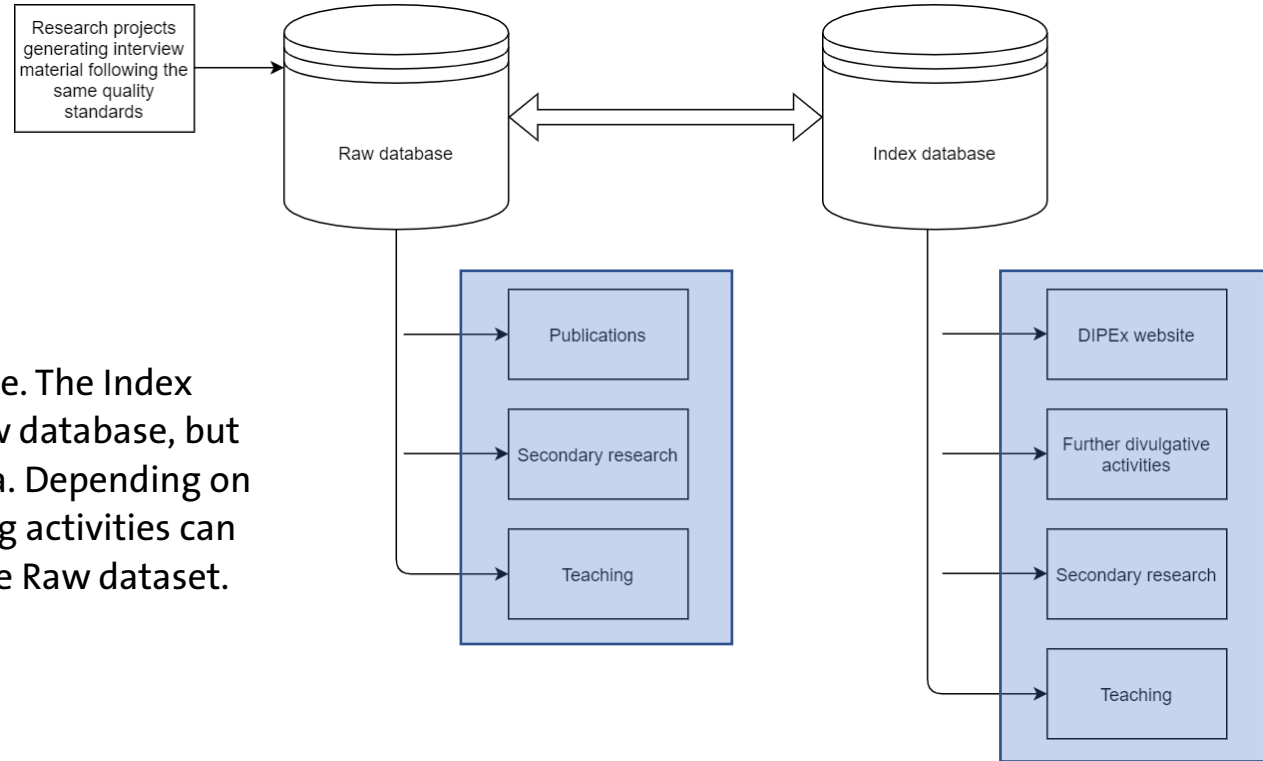
Data out:

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.

4. Data flow

Create minified dataframe for video editor

```
[5]: cols = ['ID_Experience','ITW_code', 'EXP_name_ENG', 'EXP_start_time', 'EXP_end_time', 'Consent']
df = experience_df_subset[cols]
df
```

[5]:

	ID_Experience	ITW_code	EXP_name_ENG	EXP_start_time	EXP_end_time	Consent
3	13	CMI03_05122019_EN	Charles C talks about the efficiency of the ICU	0 days 00:00:20	0 days 00:01:31	Video
4	14	CMI17_29052020_FR	For Mr. Quentin Q. everything was quick and co...	0 days 00:02:49	0 days 00:04:15	Audio
5	15	CMI01_22102019_FR	Mrs. Anna A. remembers the noise, the lights.	0 days 00:00:07	0 days 00:02:18	Video
6	16	CMI07_11122019_FR	Mr. Georges G. praises the professionalism of ...	0 days 00:01:54	0 days 00:03:06	Video
7	17	CMI13_10032020_DE	Mr Markus M always felt secure.	0 days 00:16:04	0 days 00:17:20	Audio
10	20	CMI04_05122019_FR	Mrs. Deborah D. experienced a positive atmosph...	0 days 00:09:48	0 days 00:10:56	Audio
11	21	CMI05_05122019_FR	Mrs. Eveline E sometimes felt unnoticed	0 days 00:08:12	0 days 00:08:59	Audio
12	22	CMI03_05122019_EN	Mr. Charles C. used headphones against noise.	0 days 00:13:35	0 days 00:14:52	Video
13	23	CMI06_11122019_FR	Mr. Fabio F. hears and sees, but accepts the u...	0 days 00:12:19	0 days 00:13:24	Text
14	24	CMI09_12012020_DE	Mr. IGOR I. remembers the ceiling of the room ...	0 days 00:11:23	0 days 00:12:22	Text
15	25	CMI01_22102019_FR	Mrs. Anna A. mentioned the noise by other pati...	0 days 00:04:24	0 days 00:05:15	Video
16	26	CMI21_10022020_DE	Mrs Yvonne Y. would have liked more support.	0 days 00:33:13	0 days 00:33:48	Audio
17	27	CMI21_10022020_DE	Mrs. Yvonne Y needed support for herself.	0 days 00:14:28	0 days 00:15:32	Audio
18	28	CMI12_12022020_DE	Ms. Lena L. suffered from the long waiting tim...	0 days 00:14:39	0 days 00:15:56	Audio
19	29	CMI25_30092020_DE	Mr. Clau C. was dissatisfied with his wife's c...	0 days 00:05:27	0 days 00:06:49	Text
20	30	CMI19a_06032020_DE	Mr. Urs was distressed by his wife's situation...	NaT	NaT	Audio
21	31	CMI01_22102019_FR	Mrs. Anna A talks about her hallucinations.	0 days 00:32:02	0 days 00:32:45	Video

Preparing lists of video and audio to edit for selected experiences …in 2 lines of code

4. Data flow

Filter experiences by module

This creates a slice of the experience dataframe based on the selected module.

```python
[3]: print(experience_df['Belongs_to_module'].value_counts())
     module = input("specify the sortname of the module you want to work with (e.g: AAA):")
     experience_df_subset = experience_df[experience_df['Belongs_to_module'] == module ]
     display(experience_df_subset)
```

```
CMI   41
TST   4
DEM   1
MSC   1
PDI   1
COV   1
Name: Belongs_to_module, dtype: int64
specify the sortname of the module you want to work with (e.g: AAA): CMI
```

	ID_Experience	Belongs_to_module	ITW_code	ITWee_code	ITW_original_language	EXP_start_time	EXP_end_time	EXP_duration
3	13	CMI	CMI03_05122019_EN	CMI03	ENG	0 days 00:00:20	0 days 00:01:31	0 days 00:01:11
4	14	CMI	CMI17_29052020_FR	CMI17	FRE	0 days 00:02:49	0 days 00:04:15	0 days 00:01:26
5	15	CMI	CMI01_22102019_FR	CMI01	FRE	0 days 00:00:07	0 days 00:02:18	0 days 00:02:11
6	16	CMI	CMI07_11122019_FR	CMI07	FRE	0 days 00:01:54	0 days 00:03:06	0 days 00:01:12

Getting all the experiences
belonging to a module
…in 3 lines of code

4. Data flow

Filter experiences by topic

This creates a slice of the dataframe containing only the experiences belonging to a specific topic

```
[23]:  experience_df_subset[experience_df_subset['EXP_topic'] == 'Delusion/hallucination/ dreams/anxiety.' ]
```

[23]:

	ID_Experience	Belongs_to_module	ITW_code	ITWee_code	ITW_original_language	EXP_start_time	EXP_end_time	EXP_duration
21	31	CMI	CMI01_22102019_FR	CMI01	FRE	0 days 00:32:02	0 days 00:32:45	0 days 00:00:43
22	32	CMI	CMI03_05122019_EN	CMI03	ENG	0 days 00:05:35	0 days 00:07:20	0 days 00:01:45
23	33	CMI	CMI08_16122019_DE	CMI08	DEU	0 days 00:06:06	0 days 00:07:06	0 days 00:01:00
24	34	CMI	CMI05_05122019_FR	CMI05	FRE	0 days 00:27:48	0 days 00:29:16	0 days 00:01:28
25	35	CMI	CMI10_15012020_DE	CMI10	DEU	0 days 00:06:43	0 days 00:08:20	0 days 00:01:37
26	36	CMI	CMI20_29022020_DE	CMI20	DEU	NaT	NaT	NaT
27	37	CMI	CMI23_03072020_FR	CMI23	FRE	0 days 00:20:30	0 days 00:21:18	0 days 00:00:48

Getting all the experiences
belonging to a topic
…in 1 line of code

4. Data flow

Getting all the text (in English) of the selected experiences
…in 1 line of code

Text version of selected experiences

This creates a list containing all the english text of the selected experiences

```
[29]: experience_df_subset['EXP_textversion_ENG'].tolist()
```

[29]: ["Hallucinations, I saw myself in a dark cave, yes, images like that. Sometimes yes, caves with branches, earth, dark and
yself no, there's nothing like that, you're just in the hospital in intensive care, you're getting your ceiling back. That's it.",
'And there, it was a more difficult thing. I was in a coma for four days and I was losing weight and it was difficult to feed
sense of smell and of taste, which I reckon was augmented a hundred times. So, one little grain of sugar in water was im
und me, not from a directional point of view, but that was very difficult. And, the only problem I had there then, was getti
the taste was too strong. And each time I would take a glass of even water, or orange juice, I would be vomiting, because
before I really managed to convince someone that I wasn't exaggerating. And we think that the reason was the morphine
"In every dream I was lying somewhere. I could not move. \n I was lying in a room. I uh / so, mostly in a room or in a gara
ss. Fear. Not being able to escape from the situation. So, I was just lying there. Whether it was in a restaurant or in a hos
'Well, talking like that, like they were talking to those two girls, I think that - and not talking to me; I thought I was next to
ey were doing / talking about their classes, their stuff and I was following. And I thought to myself that it\'s true that ever
ut I don\'t have a bad memory. \nI: So you always think that people, even with their eyes closed, can hear? \nE: Yes. And
nderstand. \n\nI: And afterwards, did you understand what was going on with the famous picnic, what it could be, that it
at they were having a picnic, then that they were going to eat, then that they were going to leave. But I thought they were
"I: Tell me about the dreams. What were they like?\n\nE: They were very likely things that I heard from my family. From w
wanted to fly me to the health institution (place_3). Rega (Swiss Air Rescue) was a topic. Then someone told that there w
wnstairs in the Migrolino. Down there was the hospital bed. Rega was refueling down there, waiting for me. Then they pu
no light. Then they were able to restart it. Then they drove me to the nursing home to (place_2). Like so to place_2. Then
ree bed. It was just in the hallway. Then I had such problems with my lungs and I kept wanting to tell the doctor that, but
s. For whatever reason a cow. I don't know. But, funnily enough, it was always the same doctor.",
" I: And how many of your dreams were reality? \nP: Unfortunately, more than I thought, which scared me the most. I als
atients. And so I thought for days that this was a dream and suddenly he walks past my room. All the doors are always o
ou in some way? \nE: No, I don't know. I talked to him too, but only a day later or so. And I apologized, although I don't kn
for? But then I didn't ask any further. But he was maybe a bit rough or too strict with me. I think he was also there the nig
find that bad. I found it more reassuring and she was worried about me and yes, she only meant well.\n",

4. Data flow

Applying a simple NLP pipeline to the selected text
...looks like in 2 line of code but I'm actually cheating (they are 43)

Lemma frequency and word cloud ¶

This tokenizes the selected text, calculates lemma frequencies, and creates a word cloud.

```
[48]: #Display lemma frequencies of first 10 lemmas in corpus
display(lemma_df.head(10))
# Generate word cloud from lemmas
generate_wordcloud(lemma_df, "lemma", "count", 50, "white")
```

	lemma	count	frequency
0	like	11	4.7210
1	think	9	3.8627
2	thought	8	3.4335
3	know	8	3.4335
4	coma	5	2.1459
5	yes	5	2.1459
6	talking	5	2.1459
7	room	5	2.1459
8	dreams	4	1.7167
9	lying	4	1.7167

Key message 3

We defined rules for incoming data (quality standards) and procedures for outgoing data. Being the system flexible and open, multiple strategies for outgoing data are possible.

5. Future possibilities

5. Future possibilities

New partnerships to increase incoming data

Do we need it? Do we want it? Let's stress test the concept and the structure with limit cases!

A database infrastructure allows to conceive multiple interfaces, specific for their purpose.
Currently we have one data out interface (DIPEx.ch). We could 1. probe the needs (of patients, students, relatives, researchers …) and 2. build new specific interfaces.

Qualitative data are a useful lens to study complex phenomena, and proved crucial in improving person centered care, patient empowerment, and HCP training. More data (and better data) are a crucial need to generate evidence based improvement in these areas.

New interfaces for outgoing data

Key message 4

We could use a common structure for our 'index datasets'. This would allow:
- Internal interoperability and data sharing;
- Only the data which are authorized for publication are exposed;
- No risk to compromise or expose the original data ('raw dataset');
- Endless possibilities to develop new distribution tools;
- Enhanced possibilities for secondary research;
- New collaborations (inside and outside DIPEx International).

Plus:
- Cutting to 1/14th the total cost of data infrastructures;
- Cutting to 1/14th the total cost of website development and maintenance;
- Lowering the financial threshold for new members (fair FAIR data ☺).

THANKS FOR YOUR TIME!