Learning from patients how to manage a pandemic

COVID-19 in Switzerland

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(I had my defense last Friday ☺)

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and History of Medicine

AIMS

1. Understand how qualitative perspectives can inform grounded discussions on quality of care, allowing to understand the meaning of forecasted phenomena and to track new emerging ones;
2. Understand how in such research processes participants are more than just sources of information and become actual co-actors;
3. Understand the basics of the qualitative methods with which the results are generated.

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1. Process

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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

Spitale, Giovanni, Glässel, Andrea, Tyebally-Fang, Mirriam, Mouton Dorey, Corine, & Biller-Andorno, Nikola. (2022). Patient narratives – a still undervalued resource for healthcare improvement. Zenodo. https://doi.org/10.5281/zenodo.6541400
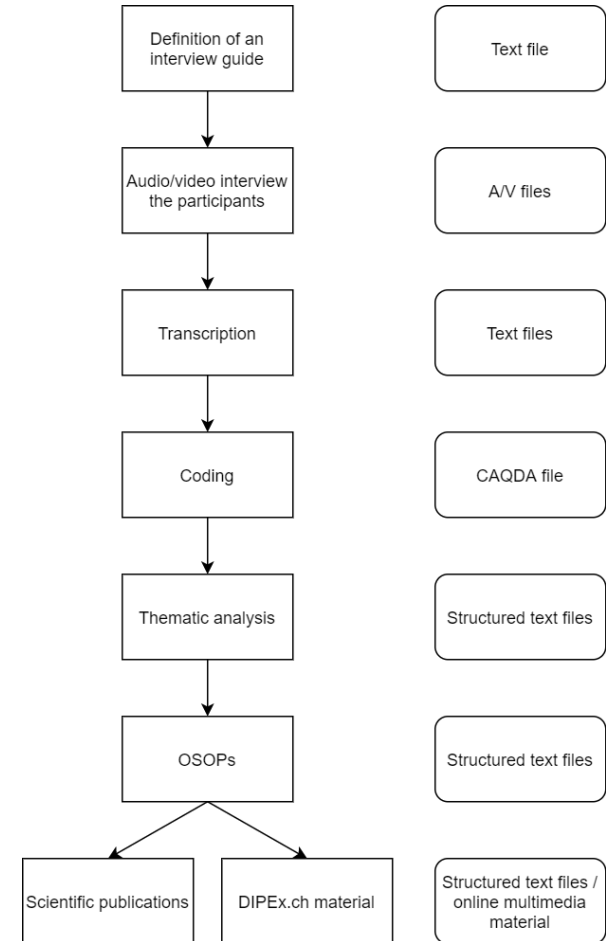
1. Process

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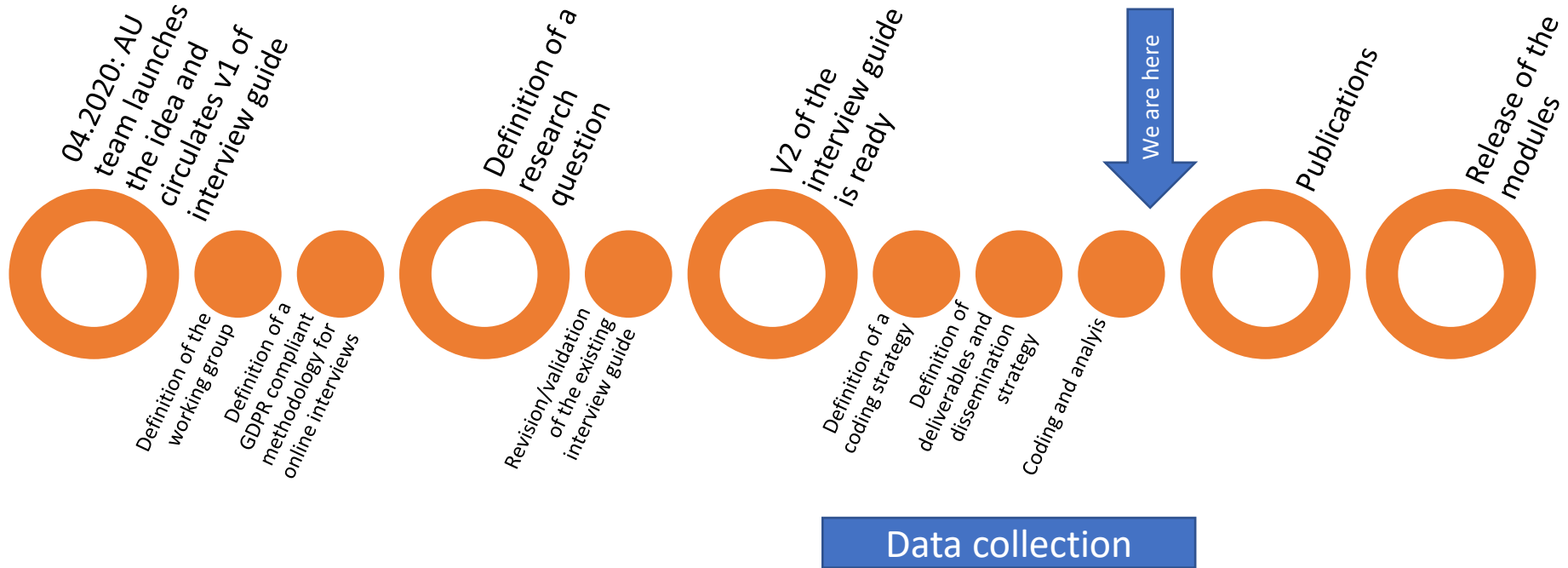
Interview files
The interview is audio and/or video recorded – according to the preferences of the itwee – and then transcribed as text.

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)

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

1. Process

2. Data

10 Countries
195 interviews
... and more are coming!

2. Dataset

Country	People	Status	ITW guide used	Target population
USA	Rachel Grob, Jane Alice Evered, Madison Wynn	7 interviews recorded	standard plus additions	Recovered patients (including healthcare workers)
the Netherlands	Nienke Verheij, Manna Alma	20 interviews coded (short, by phone)	different guide, will use the standard for new interviews	Recovered patients
Brazil	Alicia Navarro de Souza, Maria Inês Gandolfo Conceição, Ana Claudia Germani, Juliano Luna Ivone Cabral	32 interviews recorded, coding in progress	standard plus additions (spirituality, social inequality)	Recovered patients (including healthcare workers); at least 2 with long covid
Germany	Martina Breuning, Christine Holmberg, Anne Thier	15 existing itws with different itw guide (useful for comparisons) + 4 with long covid patients (standard itw guide)	different guide + standard	Recovered patients + healthcare workers
Switzerland	Nikola Biller-Andorno, Susanne Jobges, Corine Mouton Dorey, Giovanni Spitale	**13 interviews recorded; coding in progress.**	standard plus additions (icu)	recovered patients (including healthcare workers) (with a focus on ICU for a related project)
Japan	Rika Sato, Akiko Sawada, Rie Toyomoto, Emiko Wada	11 interviews recorded; coding in progress, target: 50.	standard	For COVID-19 interviews: recovered patients (9) and family members (2) (including 1 bereaved)
Spain	Vinita Mahtani, Emilio Sanz, Elisa Torres, Alicia Mora, Víctor Expósito	13 interviews recorded, coding in progress	standard	recovered patients (including healthcare workers) and one caregiver
Australia	Lorraine Smith, Renata Kokanovic, Kate Johnston-Ataata, Anna Urbanowicz	8 interviews recorded, coding in progress	standard	recovered patients (including healthcare workers when available)
UK	Lisa Hinton, Annelieke Driessen, Sue Ziebland, Tanvi Rai, Anna Dowrick, Kaveri Qureshi, Kate Hunt, Ashley Brown, Louise Locock	61 interviews recorded, coding in progress, target: 150	standard plus additions	Three studies: 1 - recovered ICU patients and relatives of deceased patients, 2 - seldom heard groups in the UK, particularly Black, Asian and other minority groups, 3 – patients with long covid
Canada	Susan Law, Ilja Ormel, Michelle Marcinow, Linda Rozmovits	15 interviews recorded, 1 transcript not returned, 14 interviews coded	standard plus additions (covid and pregnancy)	recovered patients (including healthcare workers)

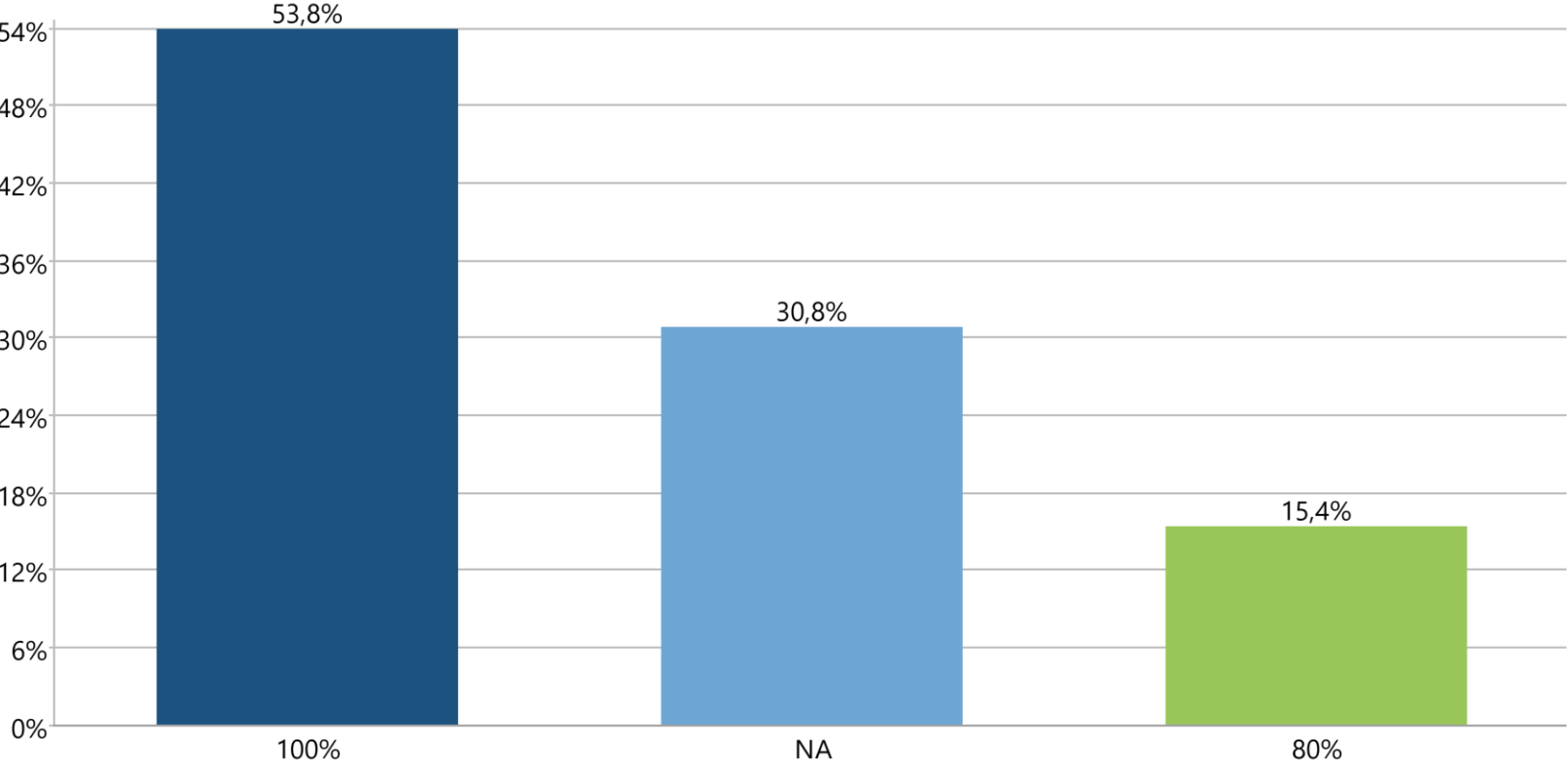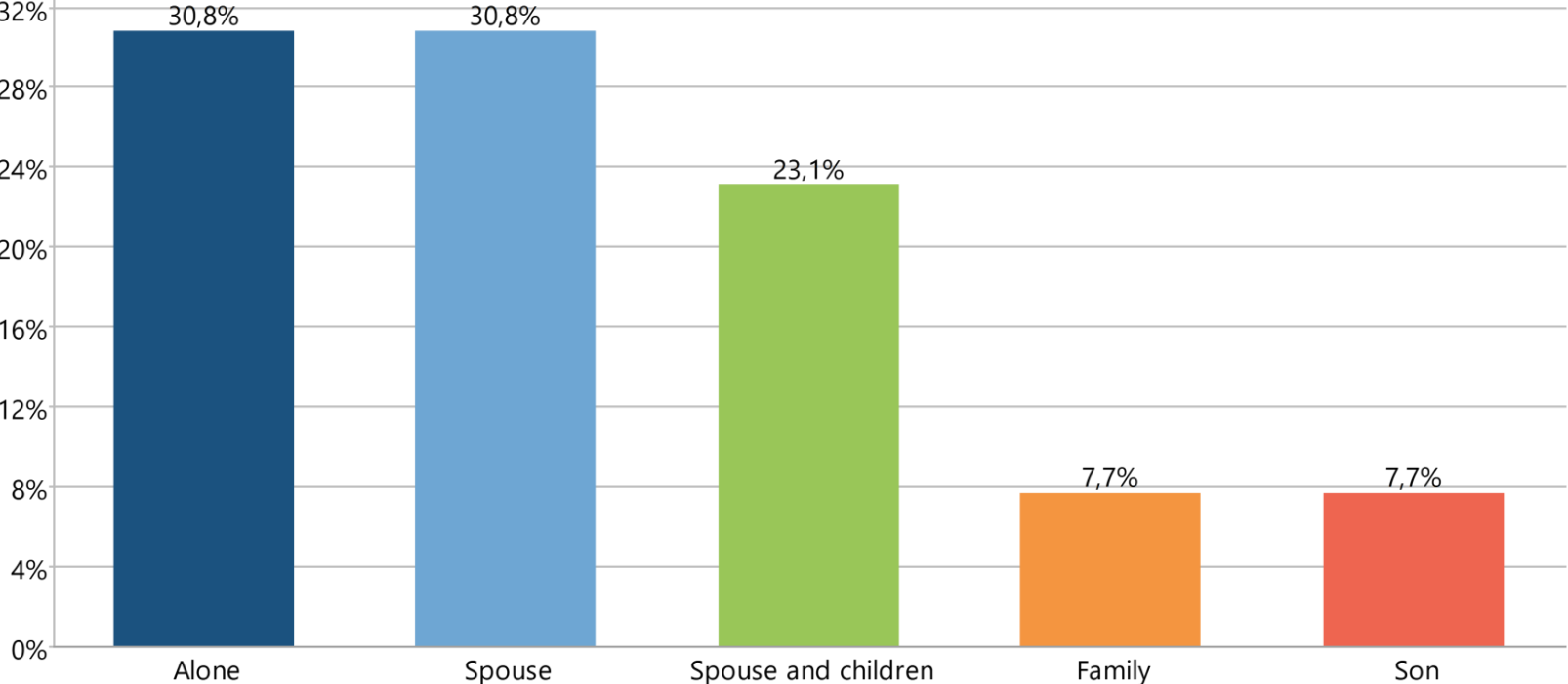# 2. Dataset

Canton/region

- 38,5% (TI)
- 23,1% (VD)
- 23,1% (ZH)
- 7,7% (AG)
- 7,7% (GE)

Legend:
- TI
- VD
- ZH
- AG
- GE
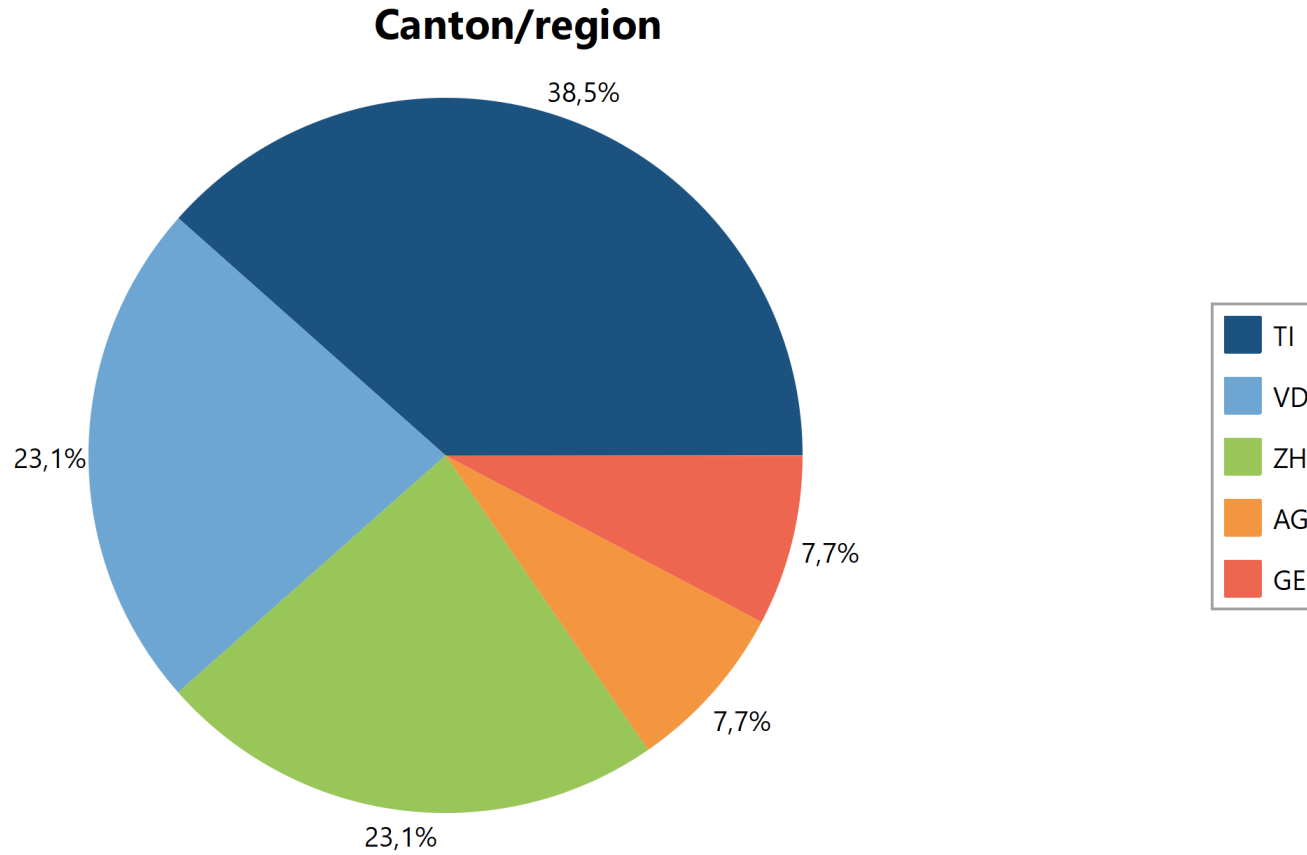
Has children
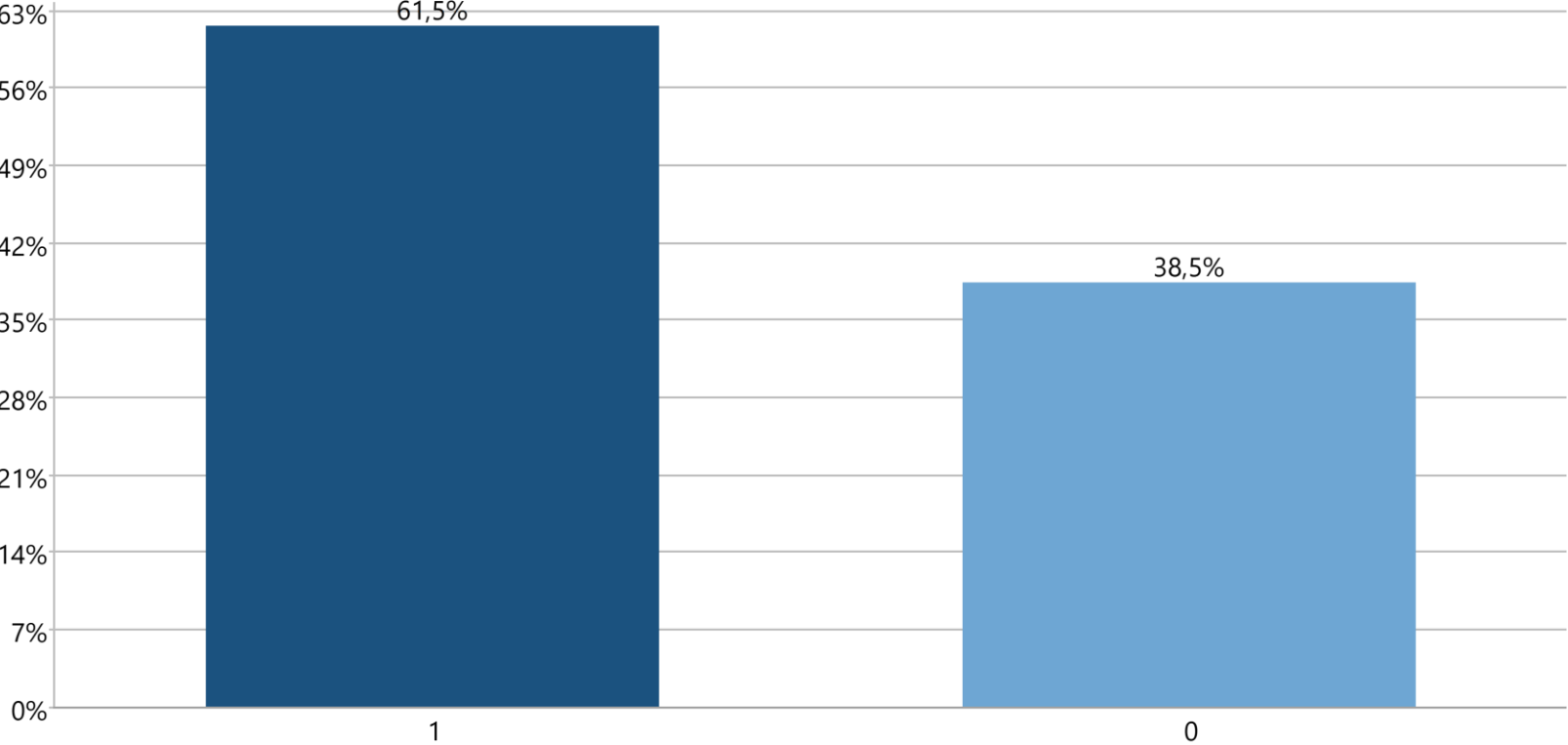
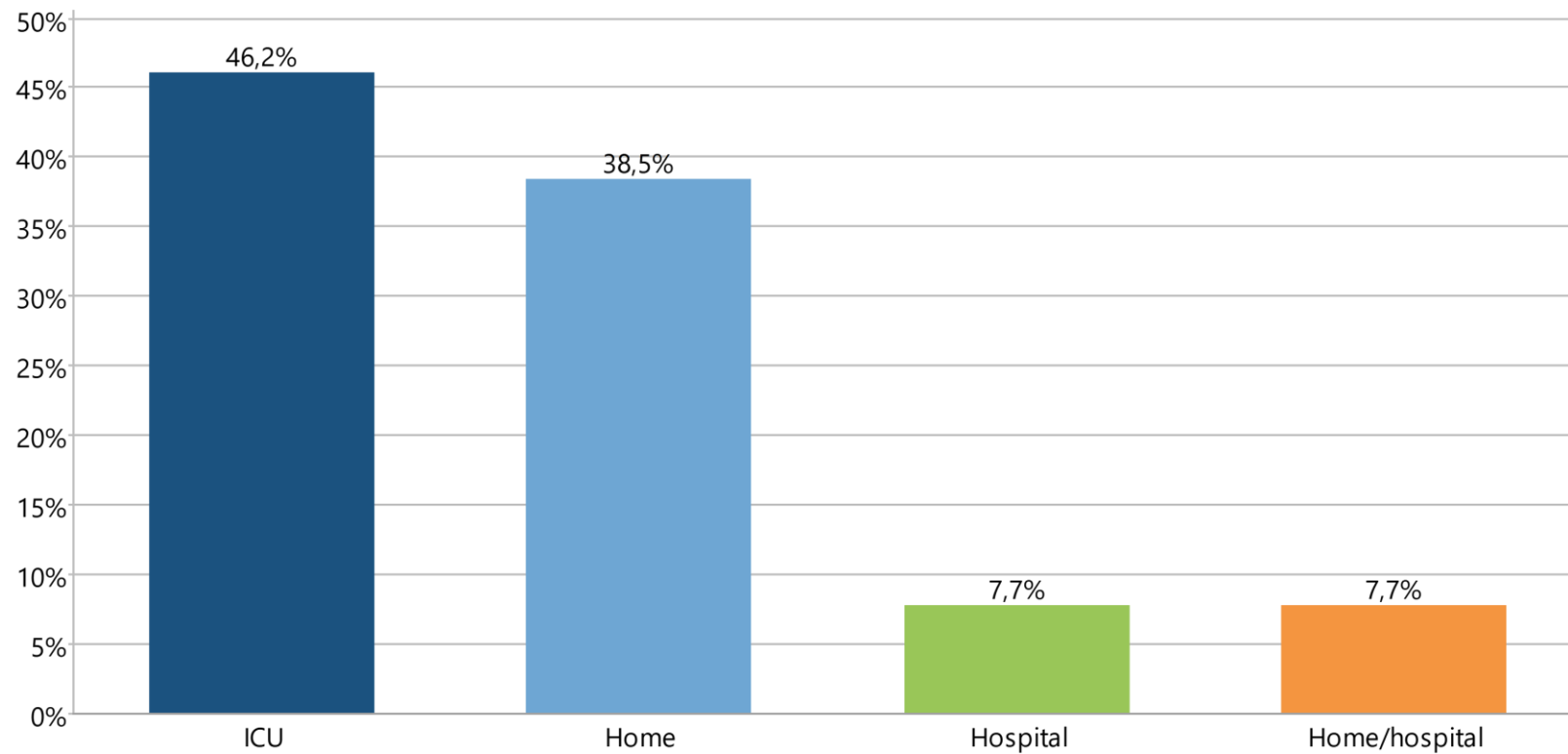**Level of employment (full time, part time, …)**

2. Dataset

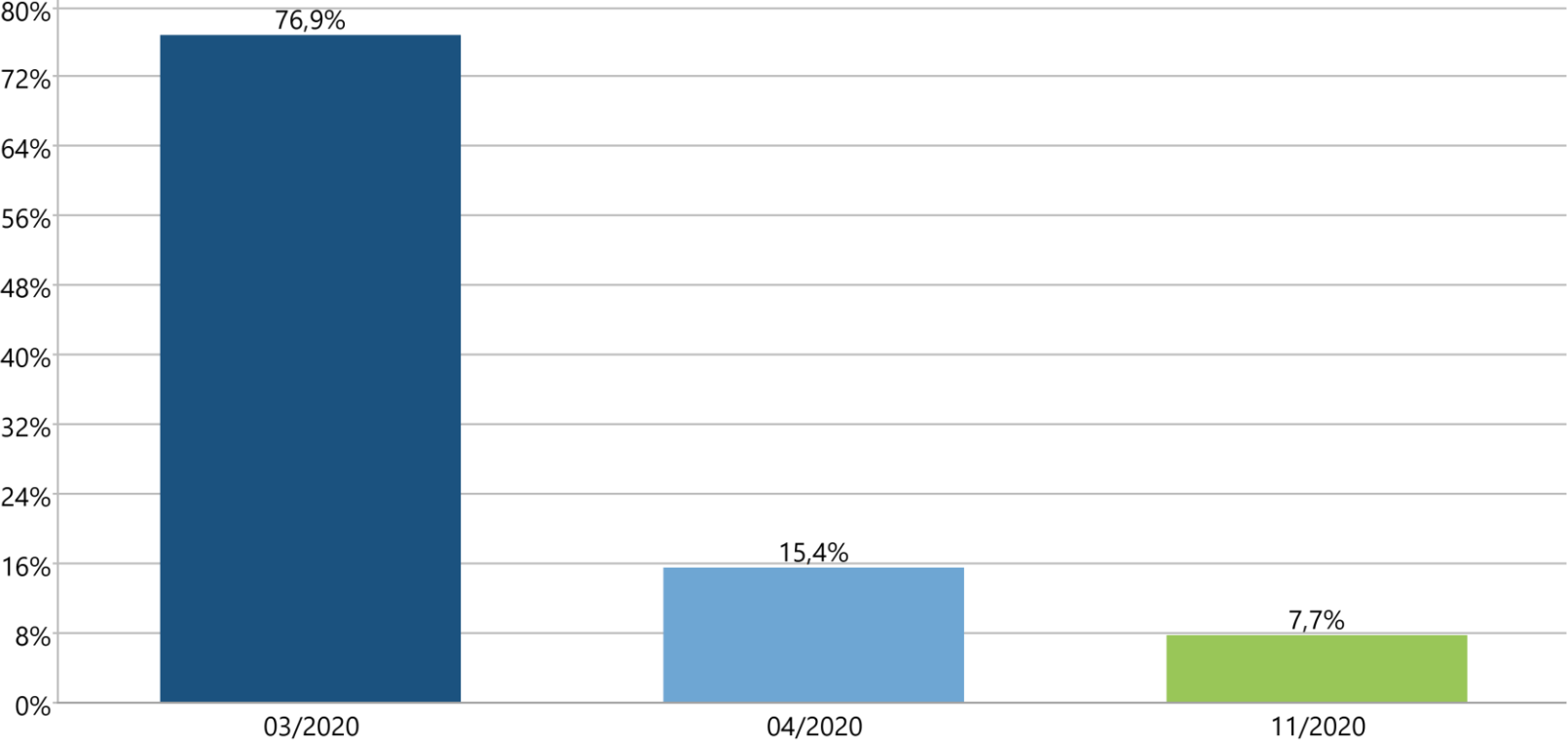**Lives with (parents, partner, others, ...)**

2. Dataset

Setting of health care (home, hospital, ICU, ...)

Time of diagnosis (year/month)

3. Into the data!

3. Into the data!

But we had wonderful neighbours who -- and a granddaughter who lives close, **who picked up food for us.** So we were in a good position.

(AU, social support)

even today I was talking to a preceptor at the Clinic, "hey, **I got a call from a friend of mine who is using chloroquine,** it looks crazy! **She cannot have chloroquine, there is no evidence."** Then I was very quiet. Until today. **My fellows don't know I used it.** [...] But the media and medical literature started **not to provide information at a speed that we needed to generate this discussion** there at the Clinic. So, we started receiving a lot of **information via WhatsApp.**

(BR, Local political conflicts/information use patterns)

E: And some guy came in and said you need to be **intubated right now,** and that's **the last thing I remember.** <<laughs>> Until I woke up like about **two weeks later in the ICU,** and the hoses in me everywhere and strapped down.

(CH, urgency and (lack of) consent)

Keep asking yourself:

Why do I think this is important?

What are my own cultural biases in interpreting this (fragment of) a narrative?

Are there any other possible interpretations?

Can this experience be transversal, or it is intrinsically connected to the context in which it happened?

What do others see here?

3. Into the data!

134 codes in the shared branch
(to have comparable data)

Complete freedom to work in the local branch
(to capture local or specific phenomena)

Next steps:

- Special issue of Social Science and Medicine: Qualitative Research in Health
    - Protocol and methods
    - Diversity, equity and inclusion
    - Uncertainty in healthcare
    - Stigma
    - Government guidance
    - Employment
    - COVID-19 in ICU
    - Long COVID
- Publication of modules

Take home message:

- Rigorous qualitative data can contribute to:
  - Person centered care,
  - Patient empowerment,
  - HCP training.
- A solid data structure allows international collaborations and comparisons;
- Comparisons can help understand what works and what does not (and what could!).

THANKS FOR YOUR TIME!

OA slides – download and reuse the deck (CC BY SA)

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