

«I woke up from a nightmare, and I was still in a nightmare»

An international study on COVID-19 patient's experiences

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DIPEX International

AIMS



1. Present how the COVID-19 pandemic is impacting our lives and the functioning of our societies;
2. Discuss how a qualitative approach to the pandemic can yield new valuable insights;
3. Present what we are doing and where we are standing
4. Tap into the knowledge of the DI community to plan the next steps

Some preliminary questions

What impact is the COVID-19 pandemic having on...

...people who, directly or indirectly, are hit by the virus?

...people who, professionally or non-professionally, assist COVID-19 patients?

...healthcare systems?

...societies in general?

1. The story so far

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Bergamo, Italy, March 2020. Morgues are so overwhelmed that military trucks are needed to dispose of the dead.

1. The story so far



Milan, Italy, March 2020. ICUs fill up at an alarming rate. Patients face sub-optimal treatment due to scarcity of crucial resources (medications, personnel, beds, ...)

1. The story so far



Vicenza, Italy, March 2020. Hospital staff keeps striving and doing their best not only to cure, but also to care...

1. The story so far



Bologna, Italy, March 2020. ...despite difficult conditions: massacring shifts, few protections, extreme pressure

1. The story so far



Zurich, Switzerland, April 2020. Societies, shaken by the pandemic, respond with flash mobs and other initiatives to support “the heroes” working in “first line”.

1. The story so far



Kriens-Pilatus region, Switzerland, April 2020. People do what they can in order to feel close, to transmit togetherness and support.

1. The story so far



Zurich, Switzerland, April 2020. The point is: we need hope, and we need to spread it as much as possible.

1. The story so far



USA, April 2020. Lockdown and quarantine measures start to have detrimental effects on societies and on people's behaviour.

1. The story so far



Swiss-German border, April 2020. Borders used to be just lines, at least in Europe. Now they manifest again as fences.

1. The story so far



Lugano, Switzerland, April 2020. We cannot meet our loved ones, and when we can the awareness of the risks makes it painful, especially for the elderly.

1. The story so far



Sion, Switzerland, April 2020. Also young generations are paying a heavy toll. Mitigation strategies work, but they are workarounds, not solutions

1. The story so far



Milan, Italy, April 2020. People try to be compliant and to get used to this new lifestyle, keeping in mind the “common good”.

1. The story so far



New York, USA, May 2020. The pandemic keeps spreading. Hart island is just one of the many mass burial sites across the world.

1. The story so far



Toronto, Canada, May 2020. Few months of pandemic are sufficient to see the rise of protests against lockdowns and preventive measures in general.

1. The story so far



Berlin, Germany, August 2020. “Small, vocal minorities” protesting against preventive measures grow bigger...

1. The story so far



Turin, Italy, October 2020. ...and angrier.

1. The story so far



March (left) and October (right).
Eight months of pandemic had this effect.

2. Our role, our responsibilities

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“In the introduction he writes that he learned the philosophy of gift **with one foot on the ground**, not in abstract, but with foundation. **The other foot, however, rises**, and the two together in movement **produce a step and a path**. So as a reader I am able to visit the many forms of this magnificent speciality of human civilization.”

(De Luca, in Spitale 2015, p. 2)

Action-oriented research: “a **participatory process** concerned with developing **practical knowing** in the pursuit of **worthwhile human purposes**. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities”

(Reason and Bradbury 2008, p. 4)

2. Our role, our responsibilities

“Patients’ stories can change curricula and achieve a Trojan horse effect as they smuggle in, and make memorable, key curriculum points. Narratives can **engage the emotions**, developing and sustaining **interest**, which is so closely related to **motivation to learn.**”

(Ziebland, Grob and Schlesinger 2020)



2. Our role, our responsibilities

“Of 4226 documents, 17 studies met the inclusion criteria. The studies investigated 10 different sources of Web-based patient narratives. Sample sizes ranged from 23 to 2458. The mean score of the quality assessment was 82.6 (range 61-100). Effects regarding five different purposes were identified as follows: **provide information, engage, model behavior, persuade, and comfort**. We found positive effects in every category and negative effects in one category (persuade).”

(Drewniak, Glässel, Hodel and Biller-Andorno 2020)



Can we make a difference?

Yes. For patients and their families.

- Recognizing and honoring the challenges these people are facing
- Providing instruments to help understanding what they are going through
- ...

Yes. For formal and non formal care givers

- Recognizing and honoring the extraordinary efforts of these people
- Providing insights and knowledge to improve the care/cure processes
- ...

Yes. For policy makers.

- From “case” to “person”. Add significance to quantitative information. Shed light on the human and subjective component of the pandemic, often neglected in public health discourses dominated by numbers.
- Provide information and feedback on what people believe and how people are faring
- ...

Yes. For our societies.

- Generate empathy, providing stories that complement information, eliciting pro-social behaviours.
- Counteract narratives that diminish the value of human life (of the elderly, of people with pre-existing conditions, ...)
- ...

Should we make a difference?

“Empirical research and theory can tell us how best to do this important work of social justice. Empirical research, and the public health statistics that surveillance and research generate, can tell us what groups are falling the most behind, and in what ways”.

(Powers and Faden 2006, p. 195)

“Act only according to that maxim by which you can at the same time will that it should become a universal law.”

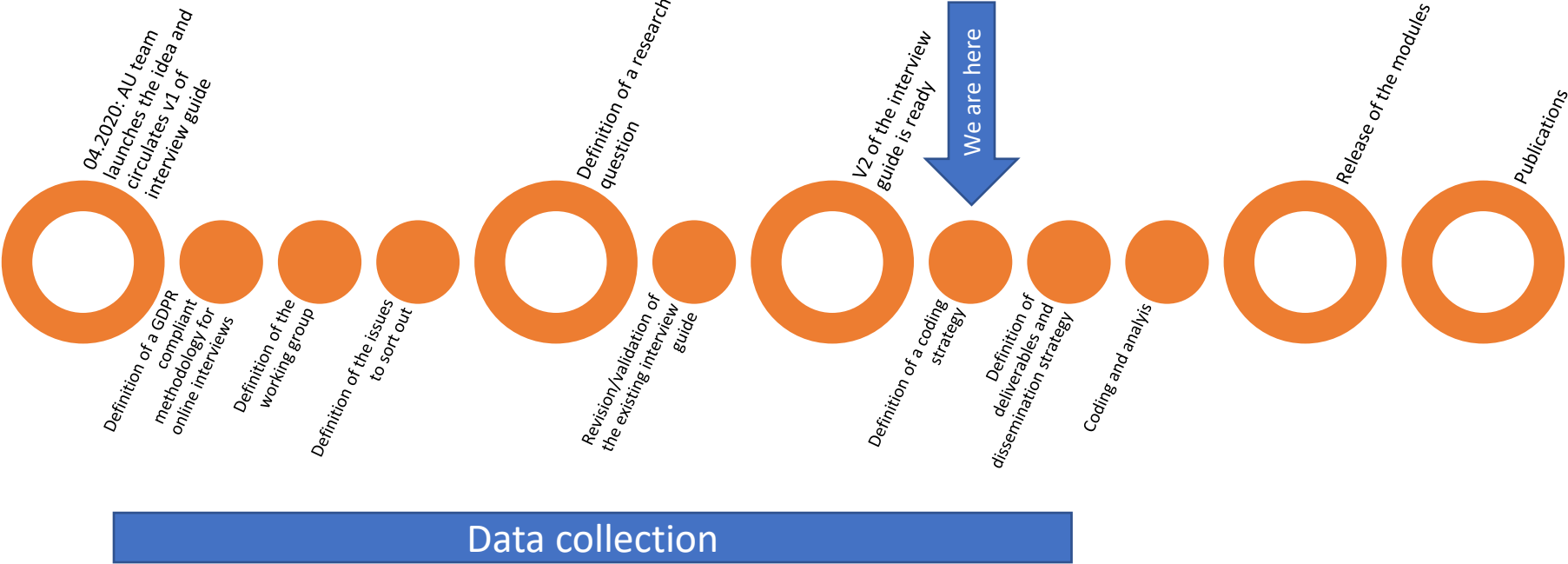
(Kant 1785)

3. What we are doing, where we are standing

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Country	People	Status	ITW guide used	Target population
USA	Rachel Grob, Jane Alice Evered, Madison Wynn	data collection starting in november	standard plus additions	Recovered patients (including healthcare workers)
the Netherlands	Nienke Verheij, Manna Alma	20 interviews coded (short, by phone); waiting for ethics approval for video interviews, hope to start in november	different guide, will use the standard for new interviews	Recovered patients
Brazil	Alicia Regina Navarro Dias de Souza, Nelson Felice de Barros	done some preliminary interviews with health care professionals, plus 2/3 patients	standard plus additions (spirituality, social inequality)	Recovered patients (including healthcare workers)
Germany	Martina Breuning, Christine Holmberg, Anne Thier	15 existing itws with different itw guide (useful for comparisons)	different guide	Recovered patients
Switzerland	Nikola Biller-Andorno, Susanne Jobges, Corine Mouton Dorey, Giovanni Spitale	data collection practically finished (11 itws); checking for theoretical saturation in order to decide whether to include more participants.	standard plus additions (icu)	recovered patients (including healthcare workers) (with a focus on ICU for a related project)
Japan	Rika Sato, Akiko Sawada, Yoko Setoyama	Applied for ethics approval to DIPEX-Japan inner ethics committee. Looking for funding for a nation-wide project. Until then, we'll do it small scale.	standard	For COVID-19 interviews: recovered patients and family members (including the bereaved)
Spain	Vinita Mahtani, Emilio Sanchez, Elisa Torres, Alicia Mora	data collection in progress, adaptable itw guide in case of need	standard	recovered patients (including healthcare workers)
Australia	Lorraine Smith, Renata Kokanovic, Kate Johnston-Ataata, Anna Urbanowicz	2 interviews completed, more to come	standard	recovered patients (including healthcare workers when available)
UK	Lisa Hinton	about to start data collection	standard plus additions	recovered ICU patients and relatives of deceased patients
Canada	Susan Law, Ilja Ormel, Michelle Marcinow	about to start data collection, ethics cleared, interviewee's recruitment in progress	standard plus additions (covid and pregnancy)	recovered patients (including healthcare workers)

3. What we are doing, where we are standing



3. What we are doing, where we are standing

In light of the DIPEX International commitment to study individual experiences that people have with health and illness, in order to understand where did people struggle and where did they learn, this research project aims to clarify what we can comprehend from the experiences of COVID-19 survivors from the Countries that participate to this study.

This research project is focused on action-oriented research, intended as “a participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities” (Reason and Bradbury 2008, p. 4).

This research project aims to **provide information and support** to patients, families, carers, friends and healthcare professionals about the experience of and recovery from COVID-19, and consequently to understand how **response strategies** (intended both on a clinical and on a social level) to the current public health crisis and to future significant threats to public health can be **reshaped and ameliorated**, learning from recovered patients with lived experience of COVID-19.

In detail, our objective is to investigate:

What are the experiences of COVID-19 survivors across the world, taking into account the **clinical trajectory** (first signs, diagnosis, treatment and recovery)?

What are the experiences of COVID-19 survivors across the world, taking into account the **social trajectory** (sources of information, role of the national governments, “horizontal communication”, trust and mistrust, inequality, uncertainty and coping with uncertainty, prevention measures - including their impact -)? How did these experiences change over time, during the different phases of the pandemic?

3. What we are doing, where we are standing

The screenshot shows a cloud storage interface with a green header bar. The header contains the logo 'oO', the text 'DIPEX International COVID-19', and 'condiviso da Giovanni Spitale'. Below the header is a navigation bar with a home icon and a right arrow. The main area displays a list of items:

<input type="checkbox"/>	Nome	
<input type="checkbox"/>	agendas and minutes	...
<input type="checkbox"/>	references	...
<input type="checkbox"/>	ITW guide - ideas.docx	...
<input type="checkbox"/>	participants and status.xlsx	...
<input type="checkbox"/>	Readme.md	...
<input type="checkbox"/>	research questions - ideas.docx	...
<input type="checkbox"/>	RQ - final.docx	...
<input type="checkbox"/>	RQ - final.pdf	...

At the bottom of the list, it says '2 cartelle e 6 file'.

<https://rattocloud.hopto.me/index.php/s/pgN7xNkcaFEJm7R>

3. What we are doing, where we are standing

The coding/analysis problem

- Quantitative complexity: 10 teams, 10-15 interviews per team -> **100/150 interviews**
- Linguistical complexity: **9 languages**: English, Dutch, Portuguese, German, Swiss German, French, Italian, Japanese, Spanish
- Contextual complexity: **10 Countries** with different healthcare systems, norms, beliefs, ...

Our hypotheses

- No sharing of raw data due to data protection reasons (and language);
- Sharing of preliminary coding trees in order to set the grounds for producing meaningful analyses on overlapping topics;
- Ideally we will have 2 categories of codes: 1. descriptive, wide codes (e.g: info sources, diagnosis, ...) and 2. context specific, interpretative micro codes - (e.g: inequality)
- Comparative work on intermediate material (heavily commented OSOPs) with itw snippets in the original language
- “Axial coding”, interpretation and analysis

3. What we are doing, where we are standing

Intermediate deliverables

- Research question
- Interview guide
- Coding trees (in English)
- OSOPs (snippets in the original language, comments in English)

Final deliverables (hypotheses)

- Publications ...?
- Module(s) ...?

4. Our questions, your ideas

SUMMARIZING:

1. What about **linguistical and contextual complexity**?

Is there anything we are not factoring in and might prove a bad surprise?

The idea is to conflate complexity without losing detail. Does it work on paper?

2. What about **our coding strategy**?

Any previous experience?

Risks and benefits? Strengths and opportunities?

3. What about **deliverables**?

Would you use the intermediate deliverables?

Would you share them on open data platforms like Zenodo or OSF?

Any clever ideas for focusing publications? What would you ask to these data?

Module(s): where shall we publish this material? DI website? National websites?

THANKS FOR YOUR TIME!

It's very, very late in this part of the world!



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