NEGOTIATING CRITICAL ANTHROPOLOGICAL INSIGHTS WITHIN THE MENTAL HEALTH LITERACY PROGRAMME

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Programme partners:

Funding:

REPUBLIKA SLOVENIJA
MINISTRSTVO ZA ZDRAVJE

Expectations of the funder – The Ministry of Health

The programme **With Raised Mental Health Literacy to Better Managing Mood Disorders** (**OMRA**); funded by the Slovenian Ministry of Health under the call *Strengthening and Protecting Mental Health in Slovenia 2017-2019*.

The rationale:

- the increase of mental health (MH) difficulties and some mental disorders (MD);
- still poor community outpatient treatment comparing to institutional treatment;
- numerous, however, poorly efficient, already established mental health programmes.

The Ministry's **expectations** through the **eligibility criteria**:

- the project should be a practical and not an academic one!;
- an efficient programme for the users;
- measurable outputs through the well-defined indicators;
- visible results → the evaluation as mandatory work package, etc.

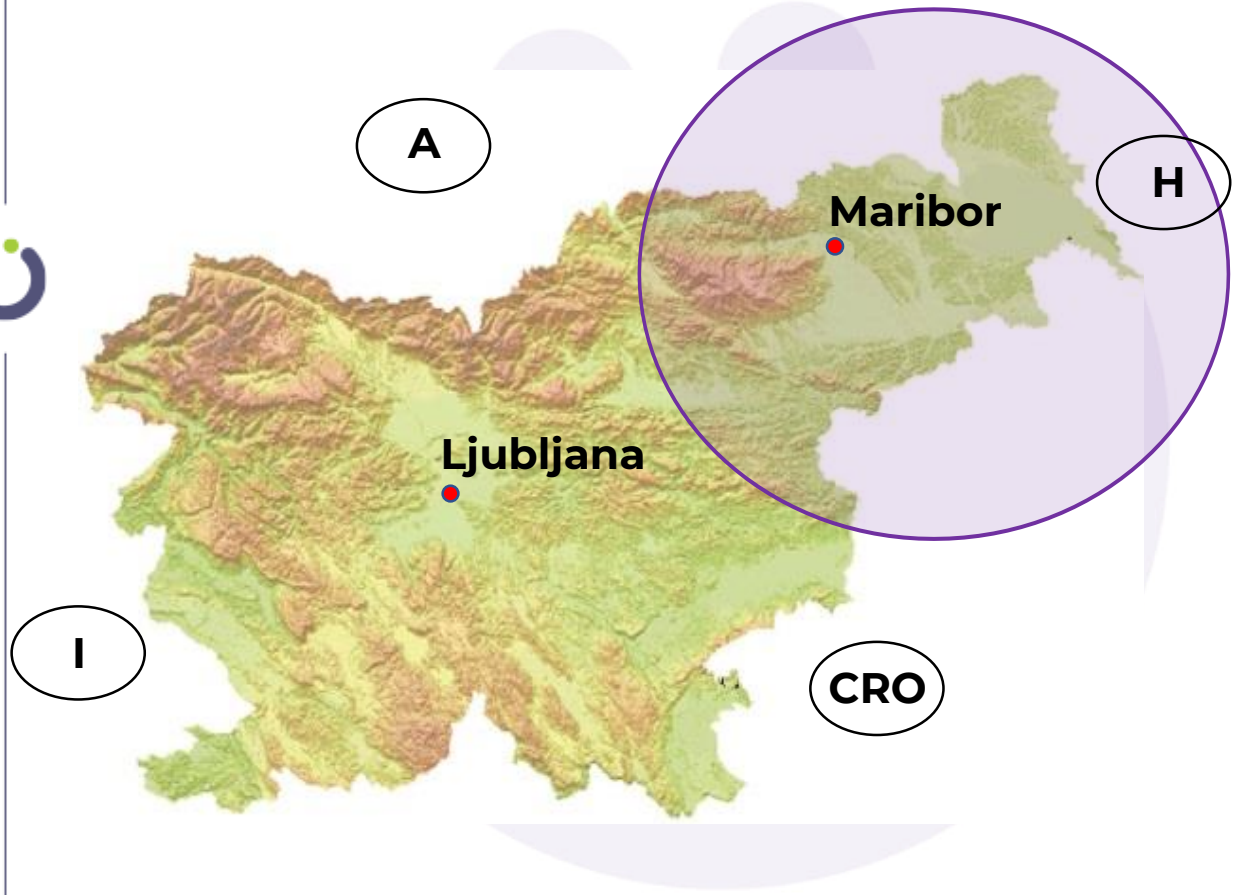
Some facts ...

slovenia as a sovereign state since 1991, **2.1 million people**, 20,271 km2 (7,827 sq mi), 213 municipalities ...

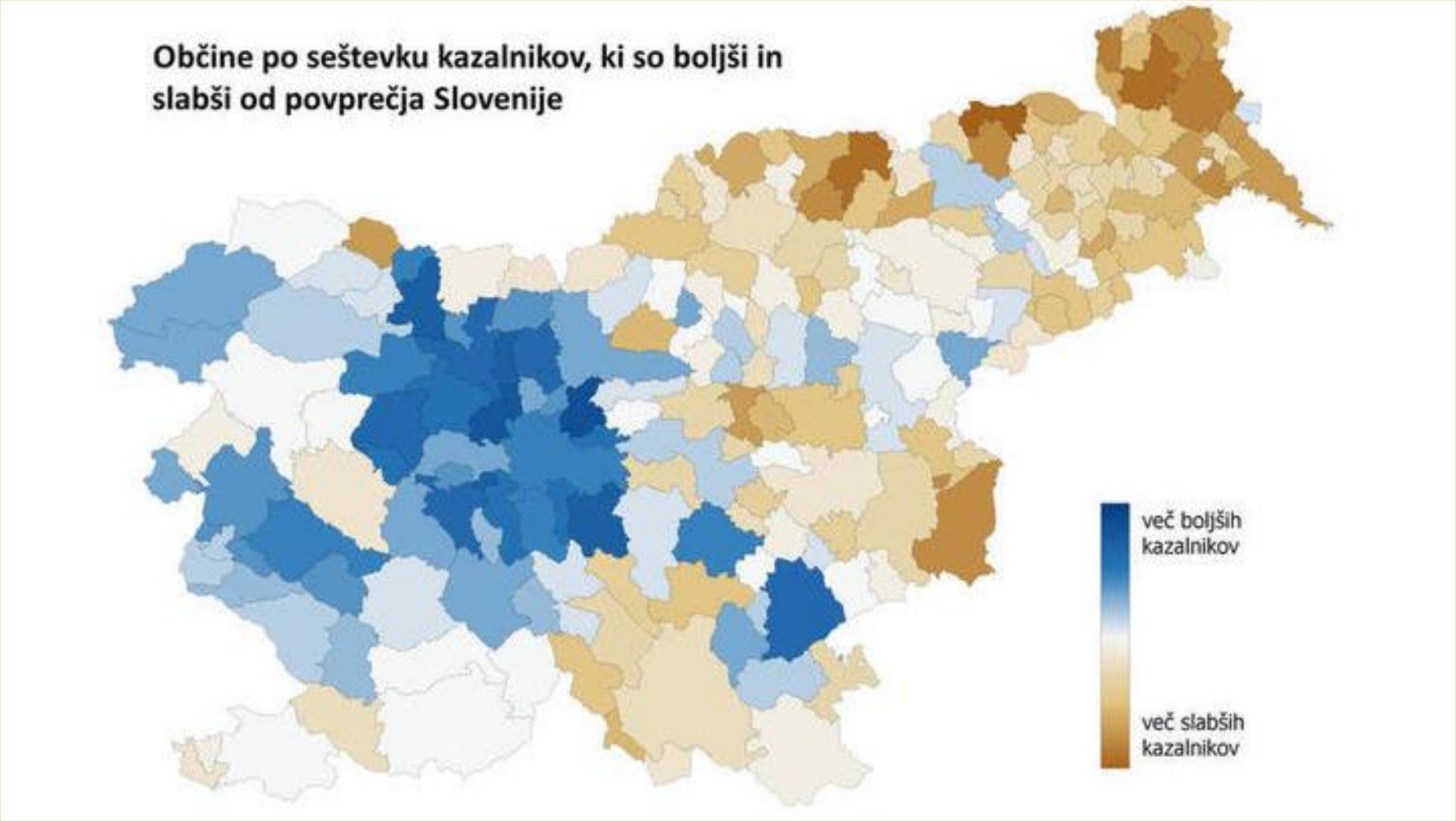
belongs to the countries with **the highest suicide rate in Europe** (in 2018, 20 deaths per 100,000 people vs. 11.3 for the EU-28).

has a **high level of MH institutionalization +** high level of MH **stigma** as a result (more than 80% of all psychiatrists are employed in psychiatric hospitals).

Huge regional differences: a poorer MH picture in North-East.



Health in general by municipalities



About the OMRA …

OMRA partners: ZRC SAZU + Institute Karakter + local stakeholders + volunteers + subcontractors …

OMRA multidisciplinary core team:

ZRC SAZU = 1 psychologist – the PI, and 2 anthropologists +

Institute Karakter = 1 psychiatrist, 1 anthropologist and 1 sociologist.

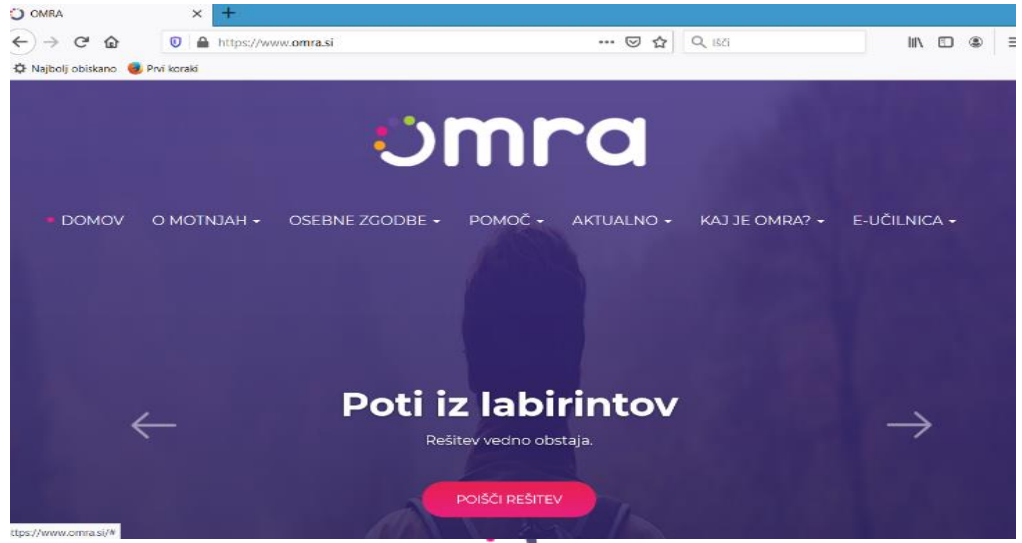
OMRA main goal: to increase knowledge about MDs in Slovenia.

OMRA target groups:

1. people with personal experience of MD (**A group**)
2. professional experience of MD (**B group**)

OMRA programme:

1. the website,
2. publications,
3. **mobile 5-hour-long workshops in NE Slovenia.**


OMRA
https://www.omra.si
Najbolj obiskano
Prvi koraki
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DOMOV
O MOTNJAH
OSEBNE ZGODBE
POMOČ
AKTUALNO
KAJ JE OMRA?
E-UČILNICA
Poti iz labirintov
Rešitev vedno obstaja.
POIŠČI REŠITEV


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DEPRESIJA IN BIPOLARNA MOTNJA RAZPOLOŽENJA
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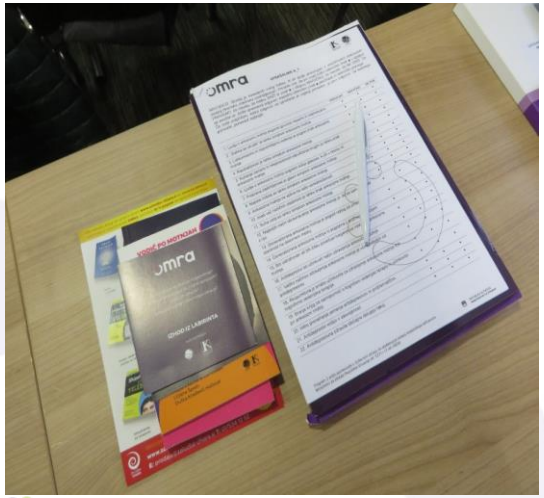
STRES IN ANKSIOZNOST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Mental health literacy

A mental health literacy (MHL) concept = professional help-seeking improves and MH stigma shrinks with mastery of information about mental illness … (Jorm et al. 1997).

The structure of mobile workshops = clear-cut sections to provide participants with the **'proper' knowledge** about:

stress / anxiety disorders / depressive disorders / bipolar disorders and coping strategies with all of them / MH (self)stigma / various options of professional help-seeking / self-help / proper communication with relatives / proper division of labour among various MH providers / local MH services + local psychiatrist.

All these sections were designed to include **pre-post-knowledge questionnaires** about MDs (anxiety, depressive and bipolar disorders) + selfstigma.

However, soon, some **fields of divergence** appeared which were necessary to discuss …

Whose knowledge to exchange?

Whose story to tell as the most proper in improving the knowledge about MDs?

Was there any room for inclusion of lived experience?

→ **A pilot study** with people with **lived experience** and those professionally in contact with them to obtain:

- emphases related to the **cultural context of NE SI**,
- research participants‘ own **voices**.

A Cultural Formulation Interview from DSM-5tm …

11 pilot personal (4 A and 7 B) and **1 group interview** (7 B) were conducted by anthropologists.

Emphases from the pilot interviews

Social and cultural dimensions of MDs should be additionally addressed:

- Various forms of education because of persistent ‘culture of shame’;
- MDs by gender and age;
- Lack of understanding of research participants‘ MD conditions (A) by their close relatives as the most painful experience;
- Various contexts of disclosure;
- MDs as a consequence of long-term unemployment in the region, particularly among men;
- MDs as a result of intensified internet violence particular in children and the youth;
- It was necessary to speak about alcoholism related to MDs, etc.

Whether and how to include all the suggestions and voices … ?

Themes about MDs (recognition, treatment, prevention) remained **unchanged** and **evidence-based**.

→ The team followed **‘proper medical knowledge’**, mostly organized around available health statistics and definitions of diseases from the **DSM-V** and **ICD-10-AM**.

The **bio-psycho-social model** in line with the particular understanding of the **context** (= **‘external’**, **‘internal’ stressors** and **‘risk factors’**) and **not lived experience** …

Selected topics = harmonised with the **standardized tests** of **wrong** and **correct items** of **evidence-based knowledge** (+ surveys on representative samples) and little room remained for lived experience.

Ethnographic diaries …

Working meetings: anthropologists negotiated to include some of the **emphases** in **the structure of the stigma lecture** …

Anthropologists insisted on **regularly taking notes about the audience's response**.

From October 2018 to June 2019, **22 five-hour-long workshops** with **956 participants** (A = 439; B = 517).

After each workshop **team's brainstorming** was organized to exchanged pro and contra arguments of divergent epistemologies and knowledge while discussing the response of the audience.

Ethnographic notes… and actions taken afterwards

- **Participants (A) disliked** worrisome health statistics presented in the introductory lecture about OMRA rationale (e. g. economic costs of their treatment, the likelihood of premature death of those suffering from BPD (**improved**),
- too professional language (**improved**),
- incomprehensible foreign professional words (**improved**).

Not all participants' comments and suggestions were taken into account …

Despite the expressed criticism over **demanding questionnaires** and **too long workshops**, these dimensions **remained** unchanged because of

- initial commitment to the Ministry,
- an academic need to follow the protocol (pre-post) for making comparisons with similar programmes worldwide and the evaluation itself.

Ethnographic diaries – the opportunity for improved explanations

Some participants **challenged a stronger emphasis on medical treatment** … → **an opportunity for** a more **refined explanation**.

To illustrate:

- A participant shared her good experience of successfully cured depression with a changed diet. → **an opportunity for explaining** different forms of depression, how to cope with them but insisting that severe and repetitive depression cannot be effectively cured by changed diet only.
- Another participant discussed a psychiatrist's obsession with medications as the most efficient treatment for severe depression, holding that when she had changed a job, difficulties vanished. → **an opportunity for discussion** about the intertwined bio-psycho-social dimensions of difficulties.

Ethnographic diaries – the opportunity for knowledge exchange inside the team!

Examples of **exoticisation, politically-incorrect formulations, de-contextualisation** and **oversimplified explanations** were **observed** and **discussed** in working meetings afterwards:

'Did you know that some minorities like the Aborigines from Australia or Inuit from Canada die because of suicide at much higher rates than the majority of Australians and Canadians... They must be more susceptible to intertwined personality, hereditary and environmental factors...' (**improved**)

'Did you know that coloured people are less diagnosed with BPD than the whites because they possessed more Neanderthal genes.' (**improved**)

'Did you know that it is an evolutionary gain that our mouth becomes dry under stress – it means that you are better prepared for a bite.' (**remained**)

When consensus was not met, the team agreed on less categorical explanations with obviously humoristic hints (evolutionary explanations) while exoticisation and racist rhetoric were abandoned.

Creative criticism by the participants through the evaluation

20 evaluation-personal (15 A + 5 B) + **2 group** (18 mostly from B) **interviews** conducted (on average) **3M after the workshop** attendance.

Besides open questions about

- the reason for participating in the OMRA workshop,
- usefulness of obtained new knowledge, etc.
- their **suggestions for improving the OMRA**

+ non-addressed but important questions were collected.

Room for improvement by participants of two FGs

- **Shorter workshops** for A,
- Themes split into **thematically organised** more **numerous** workshops,
- To address **particular groups of attendees** – employers, teachers, Roma, etc.
- **Social dimension of the so-called disease**: Addressed and considered should be **more complex cases** in terms of difficult intertwined health and social circumstances:

  'My users from remote hilly settlements do not suffer only because of depression. Usually they are as well diagnosed with chronic physical diseases and as a rule they have drinking problems. Circumstances in which they live are… well, the term social bottom cannot describe enough the misery of their living conditions.'
- Concrete **instructions for** demanding **communication**.
- To address **the 'boundary' issue** - Whether to propose help-seeking to somebody who functions well with their diagnosis.
- **Side-effects of medications**.

Room for improvement by 20 interviewees

- **To shorten** five-hour long education.
- **Single themes by days**, personal **counselling**, **repetitive workshops**, **tailored themes** to particular audience.
- **How to apply theory into practice?**

  How to confront a very embittered person … what to tell him to calm him down and to motivate him to see the light in these heavy efforts. Or else, how to make sure that another's rage doesn't make you angry (U#13)?

- How to handle the **complex and combined difficulties** – double diagnoses + poor social conditions + alcoholism, etc.

Conclusion

Fruitful collaboration = **a constant negotiation of being heard through more or less successful strategies**.

A strategy to contribute **anthropological insights** to the OMRA = **lived experience** through a pilot study + regularly taking **ethnographic diaries** + **evaluation interviews** after workshops.

Aiming at the same goal – to improve knowledge about MHD and lowering stigma related to MH difficulties – the various researchers **confronted each other with pro and contra arguments** in working meetings (brainstorming)…

In 2020 = a successfully obtained **follow-up programme** (OMRA 2020-2022) with more partners involved (+ 2 NGOs).

Taking into account **the participants' suggestions** and multidisciplinary **team's discussions**, organizing are three separate **thematic workshops** (4-hour-long OMRA1 + 4-hour-long PD + 3-hour-long stigma), **mandatory EDs** and **evaluation** as valuable practice learnt from knowledge exchange among lived experience, various researchers and stakeholders.