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Challenges in Providing Unpublished Research Data in Medicine to Grey Literature Repositories

Pavla Francová, Stephanie Krueger

National Library of Technology in Prague

8th Conference on Grey Literature and Repositories

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Scientific Project Overview

- Better visualization => **Magnetization Transfer Contrast**
- From **gelatin** over phantom with **pig lungs** to **human** healthy volunteers => open for clinical study… (any volunteers? Seriously! ☺)
- **Measuring software –> measuring protocol -> data evaluation SW**

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Goals Overview

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- Authors in **case study combine the perspectives** of active **researcher** and **information scientist**
- **Illustrate the current status** of the accessibility of scholarly outputs
- **Describe the difficulties** in searching for topic-related grey literature using a real research example
- **Provide examples** of unindexed dark scientific data
- Briefly **define what might attract** more **scientists to share** their dark data in grey literature depositories

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Keywords and Queries

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Medical Subject Headings (MeSH® Vocabulary)

Variant	Queries
A	"Magnetic Resonance Imaging" AND "Lung"
B	"Magnetization Transfer" OR "Magnetization Transfer Contrast"
C	"Magnetic Resonance Imaging" AND "Lung" AND "Magnetization Transfer"
V1	"Magnetic Resonance Imaging" AND "Lung" AND "Magnetization Transfer" OR "Magnetization Transfer Contrast"
V2	"Magnetic Resonance Imaging" AND "Lung" AND "Magnetization Transfer" OR "Magnetization Transfer Contrast" OR "Magnetization Transfer Imaging"
V3	"Magnetic Resonance Imaging" AND "Lung" AND "Magnetization Transfer" OR "Magnetization Transfer Contrast" OR "Magnetization Transfer Imaging" OR "Magnetization Transfer Contrast Imaging"

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Bibliographic Databases

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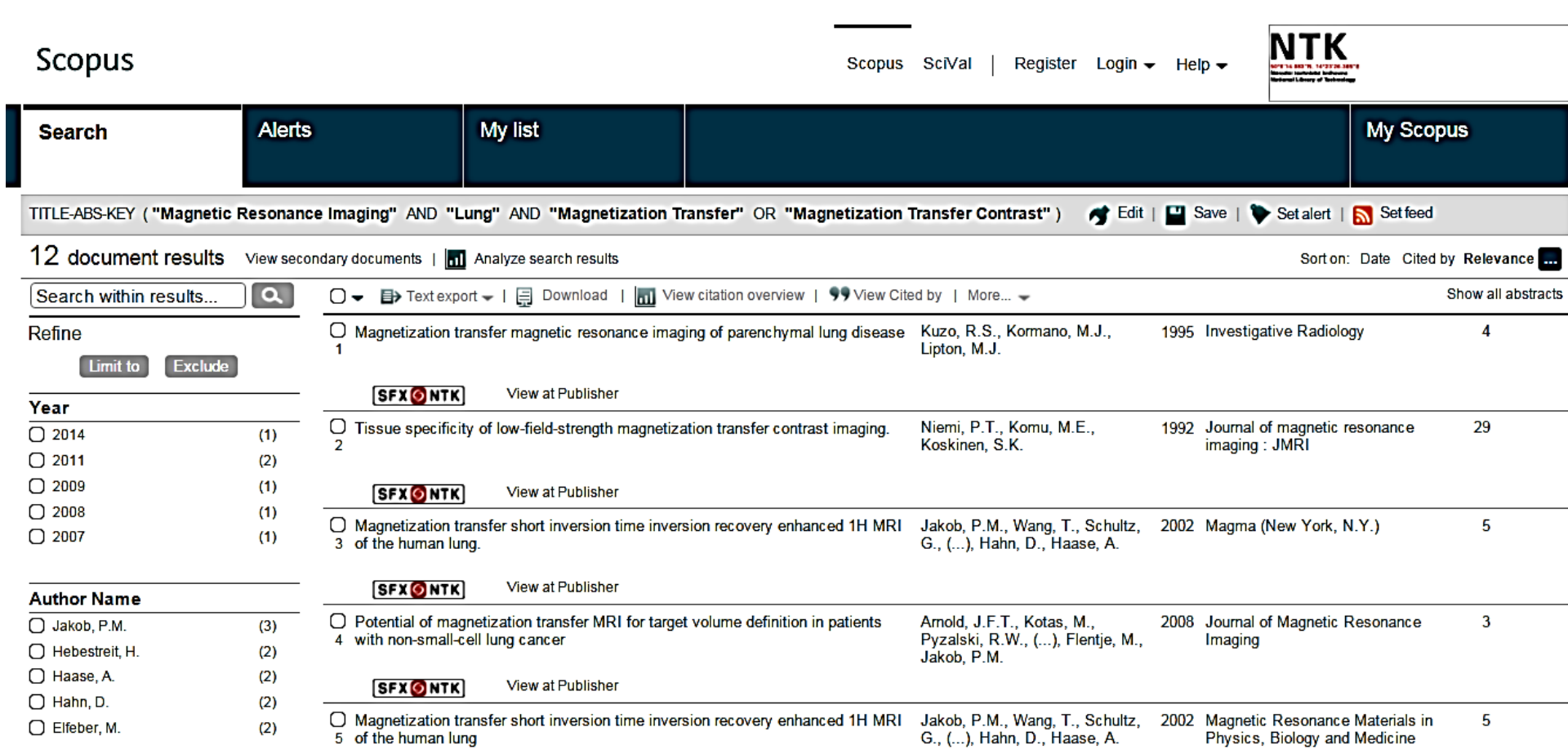
Resource Used ‖ Query	A	B	C	V1	V2	V3
PubMED	8 275	2 213	**17 [1-3]**	225	617	617
SCOPUS	25 231	3 002	**12 [1-4]**	12	12	12
Web of Science - title	351	1 398	**1 [3]**	147	395	395
Web of Science - topic	3 293	3 462	**10 [1-3,5]**	458	1 161	1 161

[1] ARNOLD J.F.T. at al. **Potential of magnetization transfer MRI for target volume definition in patients with non-small-cell lung cancer.** JMRI, 2008.
[2] JAKOB P.M. et al**. Magnetization transfer short inversion time inversion recovery enhanced1H MRI of the human lung**. Magma: MAGMA, 2002.
[3] KUZO R.S. et al. **Magnetization Transfer Magnetic Resonance Imaging of Parenchymal Lung Disease**. Invest. Radiol., 1995.
[4] NIEMI P.T. et al. **Tissue specificity of low-field-strength magnetization transfer contrast imaging**. JMIR, 1992.
[5] ARNOLD J.F. et al. **Could Functional MRI Improve Radiation Therapy Planning in Non-Small Cell Lung Cancer?** IJROBP, 2005.


Scopus

Scopus SciVal | Register Login Help

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Search Alerts My list My Scopus

TITLE-ABS-KEY ("Magnetic Resonance Imaging" AND "Lung" AND "Magnetization Transfer" OR "Magnetization Transfer Contrast") Edit | Save | Set alert | Set feed

12 document results View secondary documents | Analyze search results Sort on: Date Cited by Relevance

Search within results...

Refine

Limit to Exclude

Year

2014 (1)
2011 (2)
2009 (1)
2008 (1)
2007 (1)

Author Name

Jakob, P.M. (3)
Hebestreit, H. (2)
Haase, A. (2)
Hahn, D. (2)
Elfeber, M. (2)

Text export | Download | View citation overview | View Cited by | More... Show all abstracts

1 Magnetization transfer magnetic resonance imaging of parenchymal lung disease — Kuzo, R.S., Kormano, M.J., Lipton, M.J. — 1995 — Investigative Radiology — 4
SFX NTK View at Publisher

2 Tissue specificity of low-field-strength magnetization transfer contrast imaging. — Niemi, P.T., Komu, M.E., Koskinen, S.K. — 1992 — Journal of magnetic resonance imaging : JMRI — 29
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3 Magnetization transfer short inversion time inversion recovery enhanced 1H MRI of the human lung. — Jakob, P.M., Wang, T., Schultz, G., (...), Hahn, D., Haase, A. — 2002 — Magma (New York, N.Y.) — 5
SFX NTK View at Publisher

4 Potential of magnetization transfer MRI for target volume definition in patients with non-small-cell lung cancer — Arnold, J.F.T., Kotas, M., Pyzalski, R.W., (...), Flentje, M., Jakob, P.M. — 2008 — Journal of Magnetic Resonance Imaging — 3
SFX NTK View at Publisher

5 Magnetization transfer short inversion time inversion recovery enhanced 1H MRI of the human lung — Jakob, P.M., Wang, T., Schultz, G., (...), Hahn, D., Haase, A. — 2002 — Magnetic Resonance Materials in Physics, Biology and Medicine — 5

[1] ARNOLD J.F.T. at al. **Potential of magnetization transfer MRI for target volume definition in patients with non-small-cell lung cancer.** JMRI, 2008.

[2] JAKOB P.M. et al**. Magnetization transfer short inversion time inversion recovery enhanced1H MRI of the human lung**. Magma: MAGMA, 2002.

[3] KUZO R.S. et al. **Magnetization Transfer Magnetic Resonance Imaging of Parenchymal Lung Disease**. Invest. Radiol., 1995.

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Full-text Databases

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Resource Used ‖ Query	A	B	C	V1	V2	V3
EBSCOhost	2 235	834	**4**	44	208	67 371
ScienceDirect	42 465	5 860	**300**	300	300	300
SpringerLink Biomedical Sciences	5 872	815	**83**	156	322	322
SpringerLink Medicine	26 778	1 989	**387**	681	1 016	1 016
SpringerLink Public Health	1 215	138	**45**	65	76	76
Wiley Online Library	26 109	5 796	**711**	1 489	2 073	2 073
ProQuest Dissertations & Theses	9 483	6 681	**282**	855	2 317	2 317
ProQuest Health and Medicine	43 772	6 681	**282**	855	2 317	2 317

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Institutional Repositories

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Resource Used ‖ Query	A	B	C	V1	V2	V3
Universität Würzburg	143	18	**14**	143	143	143
Friedrich-Alexander-Universität Erlangen-Nürnberg	88	7	**3**	88	88	88
Eberhard-Karls-Universität Tübingen	643	509	**710**	755	755	755
Forschungszentrums Jülich	4	3	**0**	0	0	0
Ruprecht-Karls-Universität, Heidelberg	161	2	**23**	0	0	0
Health Services Research Projects in Progress	8	0	**0**	0	0	0

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Medical Repositories

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International European Repositories	A	B	C
Electronic Theses Online Service (ETHOS) | British Library	22	2	0
Center for Research Libraries Foreign Dissertation	537	1	538
DART-Europe E-theses Portal	30	18	30
National Institute for Health and Clinical Excellence (NICE)	24	0	0
Public Health England	1	0	0
UK Department of Health	22	172	95
Nature Precedings	15	1	0
World Health Organization	93	0	0

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Data Overview

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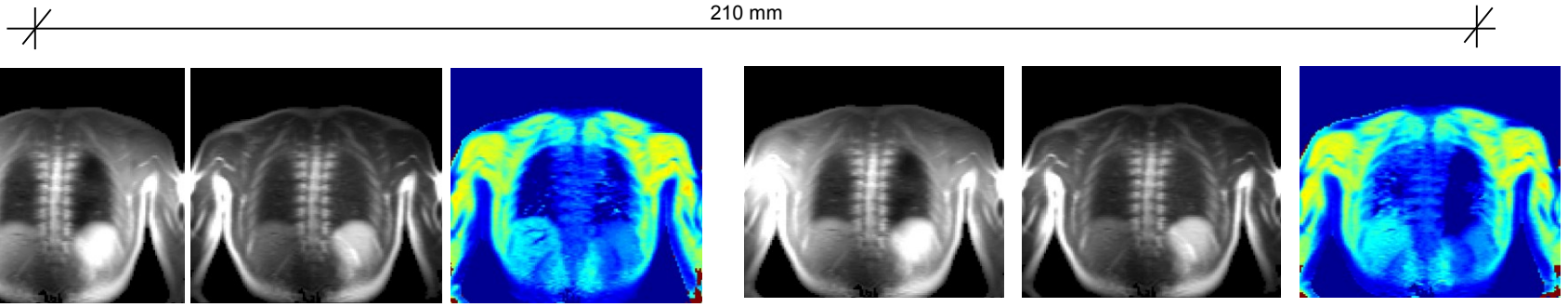
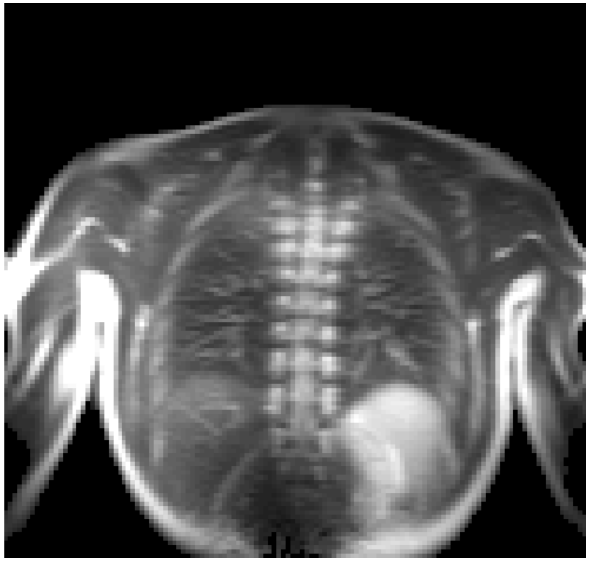
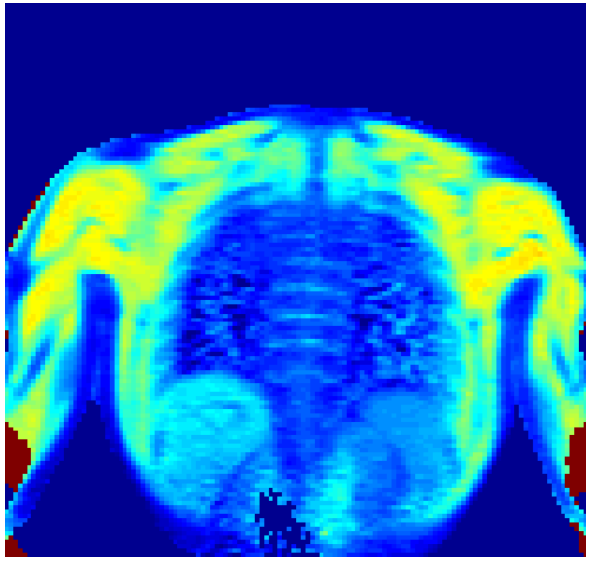
Data Type	Size
Single data set (i.e., an individual MRI image received using a measuring protocol)	**3 - 4 MB**
RAW data sets (total images per scientific project)	**80 - 100 GB**
Laboratory notes and diaries (evaluation of single data sets, parameters)	**--- MB**
Summaries and statistics (comparison of data sets per chosen parameter)	**--- MB**
Conference materials (posters, presentation, supportive materials)	**2 - 3 GB**
Supportive materials for peer-reviewed outcomes (images, tables, graphs)	**--- MB**
Programming files (measurement and evaluation files, necessary .exe programs)	**35 - 60 GB**
Research-related literature and data (related articles, images etc.)	**2 GB**
Total size of all the related project materials	**100 - 170 GB**

RAW Data and MRI Images







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Laboratory Diary

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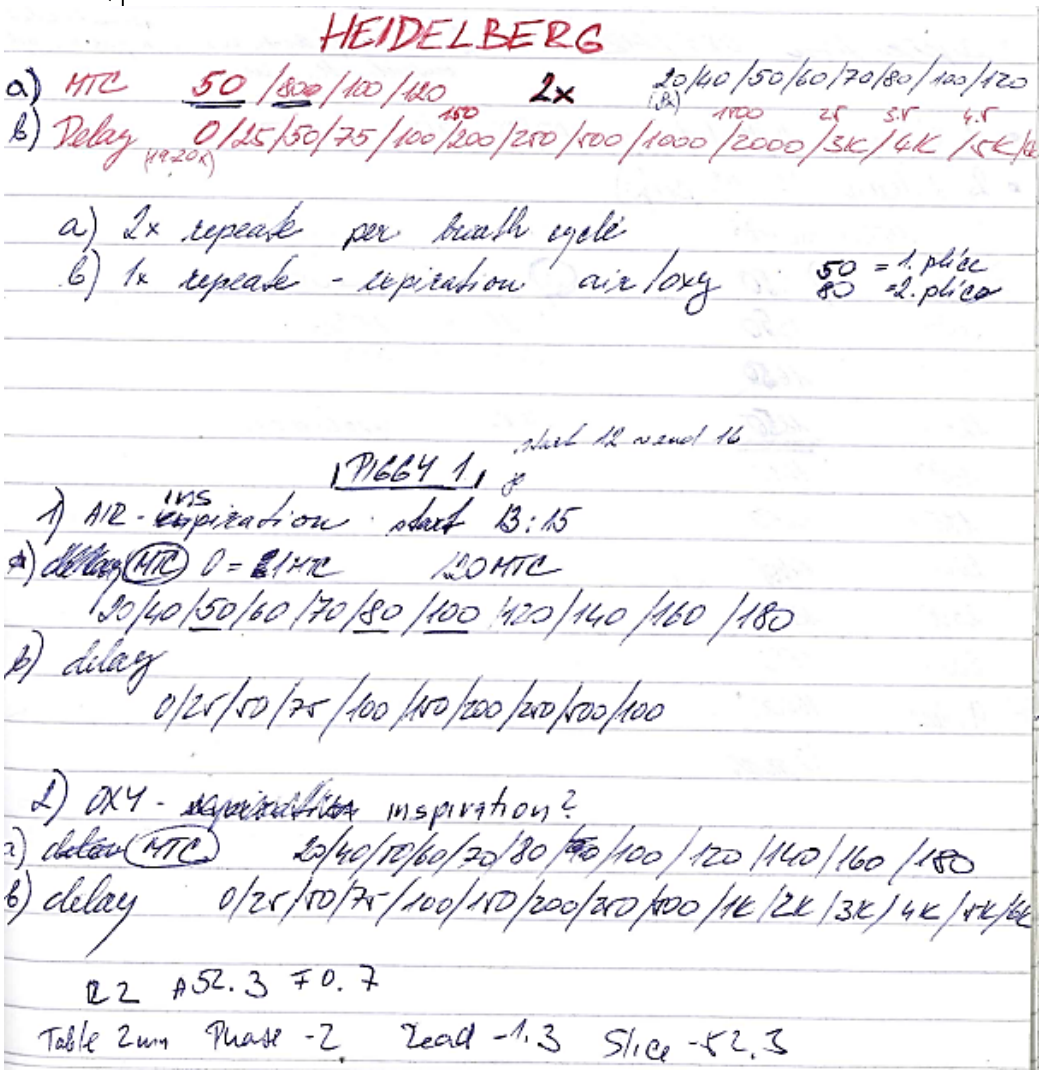

- **Hand-written example**
  - Usually supported by materials in electronic format
- Individual organization
- **Side notes**
- Personal markings
- **Ideas and thoughts during measurement**

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Laboratory Diary

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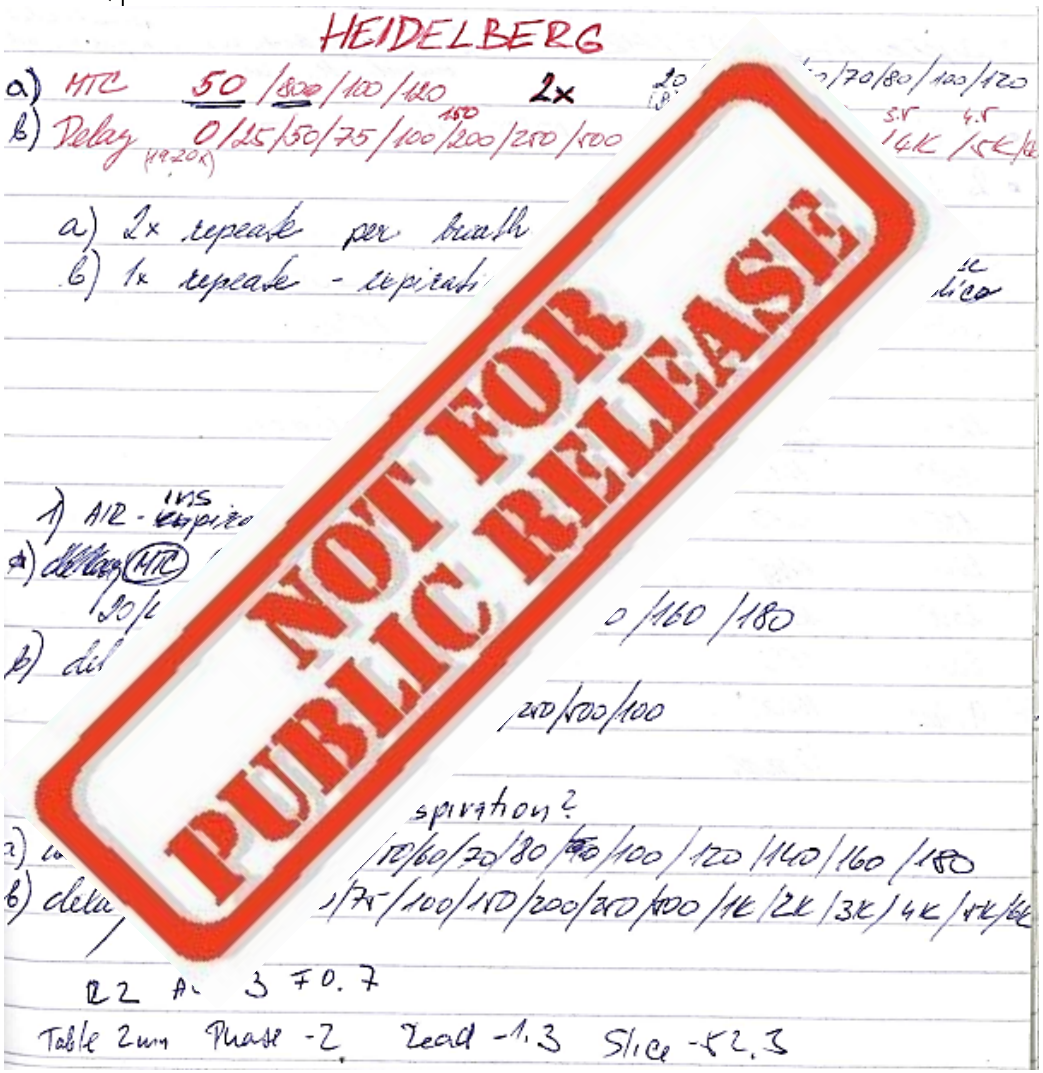

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Individual Data Set Report

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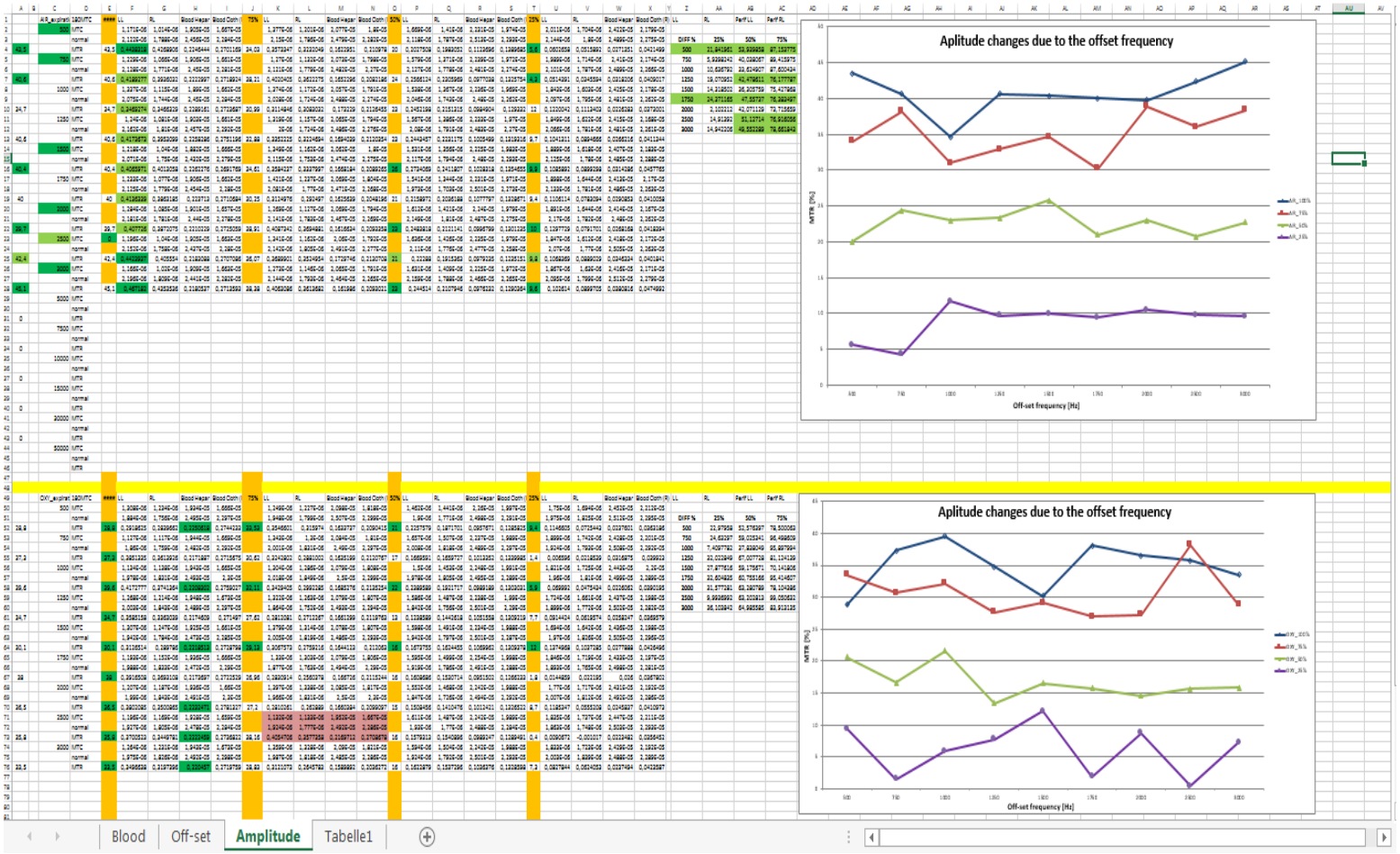

- Personal organization and markings
- Orientational data visualization

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Individual Data Set Report

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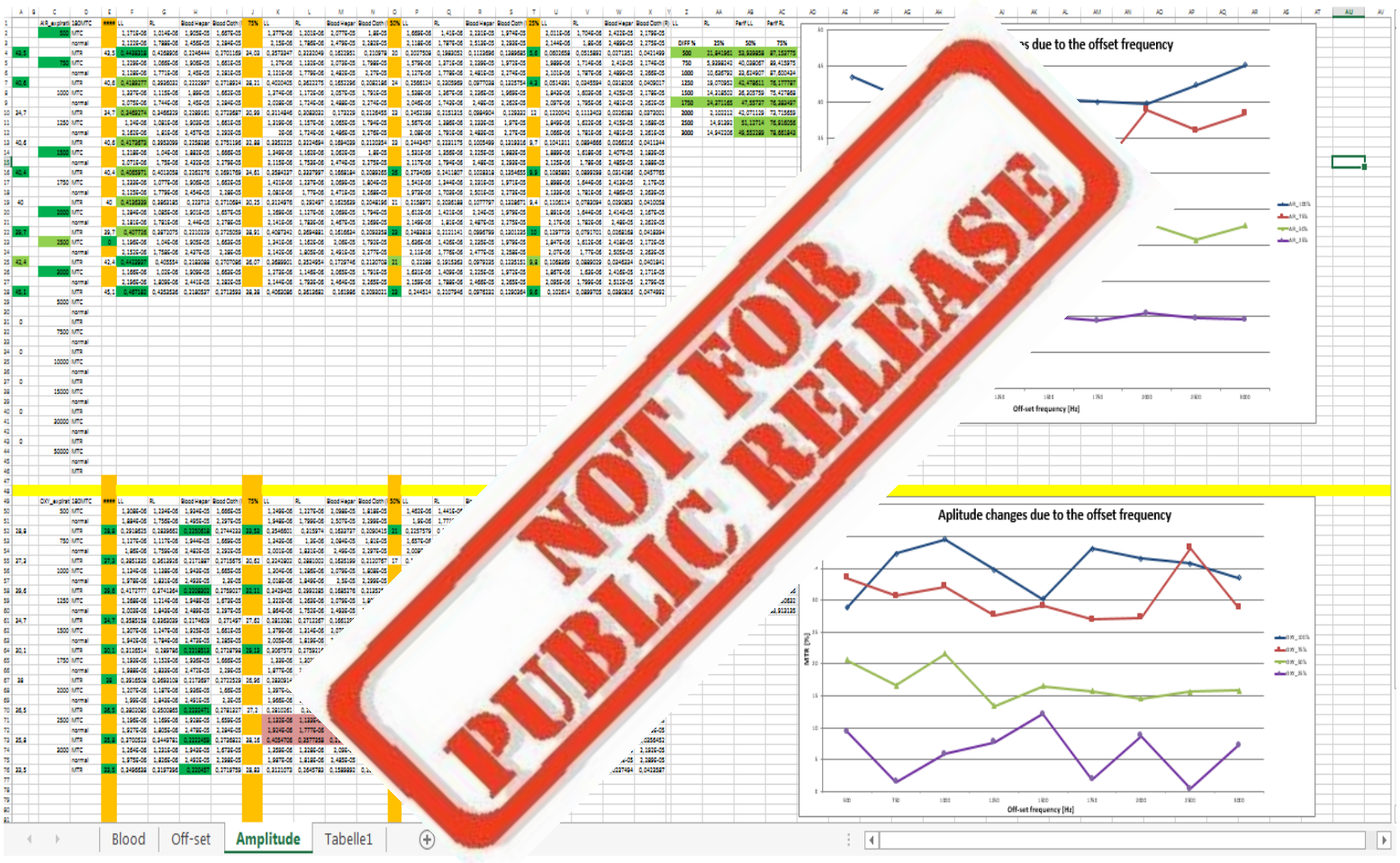

- Personal organization and markings
- Orientational data visualization

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From Dark to Grey Data

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Challenges technical

- Storage for 1-100 terabits (RAW data) per scientific project
- No universal forms for individual data types
- Organization and indexing of metadata

Challenges ethical

- Human data
- Missing guidelines
- Legal issues – rights and licenses

Challenges personal

- Search for related data
- Writing
- Statistics
- Style (language / graphic)

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Recommendations

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- **Ethical guidelines** for biomedical dark data, including personal information to prevent their misuse/release to public (non-medical) audience
- **Determine** which **data sources** should be stored
- **Prepare universal formats and platforms**
- Proper **structure of outputs** for indexing and retrieval
- **Develop an overall searching tool/platform** for all the (at least topic-related) repositories

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Summary

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- **Grey literature** is not **only conference materials** and **dissertations**
- **Scientists' needs** can be very specific **according to** each individual's **research topic and interest**
- **Case study in Biomedical Engineering** involves information directly-related to a specific research topic and presents different types of dark data
- **To encourage** more **scientists to share** dark data in grey literature repositories, it is necessary to prepare highly user (i.e., scientist) friendly environments
  - **Prepare standards** for different types of dark data
  - **Ethical guidelines** for the field of Biomedicine
  - Develop **search tools** and platforms for searching across (all) possible resources/repositories

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Discussion

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