

Annual conference EMSP

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Berlin, Germany

From Diagnosis to Access:
Data-Driven Solutions for
MS, NMO and MOGAD

Building Fairer Future for Patients

#EMSP2026



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MULTIPLE SCLEROSIS
PLATFORM



Deutsche
Multiple Sklerose
Gesellschaft
Bundesverband e.V.

Ethical challenges in data collection and use

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Introduction

1. Psychology



UNIVERSITY OF AMSTERDAM

2. Meta-science in Psychology

TILBURG



UNIVERSITY

3. Meta-science in Medicine



Berlin Institute
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@Charité



Research questions

1. What ethics-related information do patients want from registries?
2. What preferences do patients have about how ethics-related information is communicated by registries?

Ethics-related information

- Governance & Conflicts of Interest
- Consent Mechanisms
- Privacy & Data Protection
- Use & Access Policies
- Handling of Incidental Findings
- Research Transparency



Joint Action 3

MILESTONE

Milestone 5.15 Final validated Standards Tool for Registries in HTA prepared

Date of submission	30-09-19
Work package	5
Activity Centre	Post-Launch Evidence Generation (PLEG) and Registries – Strand B2
Author(s)	National Institute for Health and Care Excellence, NICE (UK) Croatian Institute of Public Health, HZJZ (Croatia) Agency for Health Quality and Assessment of Catalonia, AQUAS (Spain) French National Authority for Health (Haute Autorité de Santé), HAS (France) - work package lead
Dissemination level	Public



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Registries for Evaluating Patient Outcomes: A User's Guide

Fourth Edition



Kalkman et al. *BMC Medical Ethics* (2019) 20:21
<https://doi.org/10.1186/s12910-019-0359-9>

BMC Medical Ethics

RESEARCH ARTICLE Open Access

Responsible data sharing in international health research: a systematic review of principles and norms

Shona Kalkman^{1*}, Menno Mostert¹, Christoph Gerlinger^{2,3}, Johannes J. M. van Delden¹ and Ghislaine J. M. W. van Thiel¹

Check for updates

Interviews with MS patients

- Interviews with MS patients and MS patient representatives
- 60-90 minutes via Teams

Total participants = 21	
Gender	n (%)
Woman	13 (61.9)
Man	8 (38.1)
Country	n (%)
Belgium	4 (19.0)
Croatia	2 (9.5)
Denmark	4 (19.0)
Germany	2 (9.5)
Greece	2 (9.5)
Netherlands	2 (9.5)
Portugal	1 (4.8)
Serbia	2 (9.5)
Spain	2 (9.5)

Total participants = 21	
Age	average [min; max]
	48.8 [31; 80]
MS Duration	average [min; max]
	16.9 [3; 30]
Representative	n (%)
Yes	14 (66.7)
No	7 (33.3)
Registry Enrol.	n (%)
Yes	11 (52.4)
No	7 (33.3)
Not sure	2 (9.5)
NA	1 (4.8)

Conclusions

→ Important deciding factors for participation: **Who, what, why, which**

“What i think we need to know? Where is the data going? So that's my only thing.” – Participant 33

“But it would be important to know what exactly are they going to do with my data. So what are the questions in layman's English? Explain what you want to achieve and why.” – Participant 64

Conclusions

→ Information on personal or aggregate results was seen as a strong benefit of participation

“I don't think that it needs to be any kind of reward any kind of financial incentive or anything like that. Really, just knowing that you're participating in something that will be helpful and beneficial to other patients.” – Participant 14

“[I want to know] what is done with that information to show that it's not just sitting there for researchers to research, but there's actually an output” – Participant 20

Conclusions

→ Trust emerged as a key factor in terms of information needs and communication preferences

“I would normally accept entry into registries which are already part of trusted institutions of some kind. For example, known universities or the public system.” – Participant 7

“Especially as a person with a chronic illness, I wouldn't want to have to get that level of information. If I didn't have an initial feeling of trust, I just wouldn't go into it.” - Participant 7

“Via the channels that patients trust . So that's either their medical people or like [...] you know patient organizations, patient advocates” - Participant 65

Overarching conclusions

- Patient registries need to cater to the preferences of patients because without patients there are no patient registries
- Patient registries can establish trust by communicating transparently about what types of research the data will be used for and what the outcomes of already conducted research are



Thank you!

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