

WECCAN

Workgroup of European
Cancer Patient Advocacy Networks



**PATIENT FOCUSED
MEDICINES DEVELOPMENT**

Reforming agreements between patient advocacy and the pharmaceutical industry

Reasonable agreements between patient advocacy and the pharmaceutical industry (RAPP)



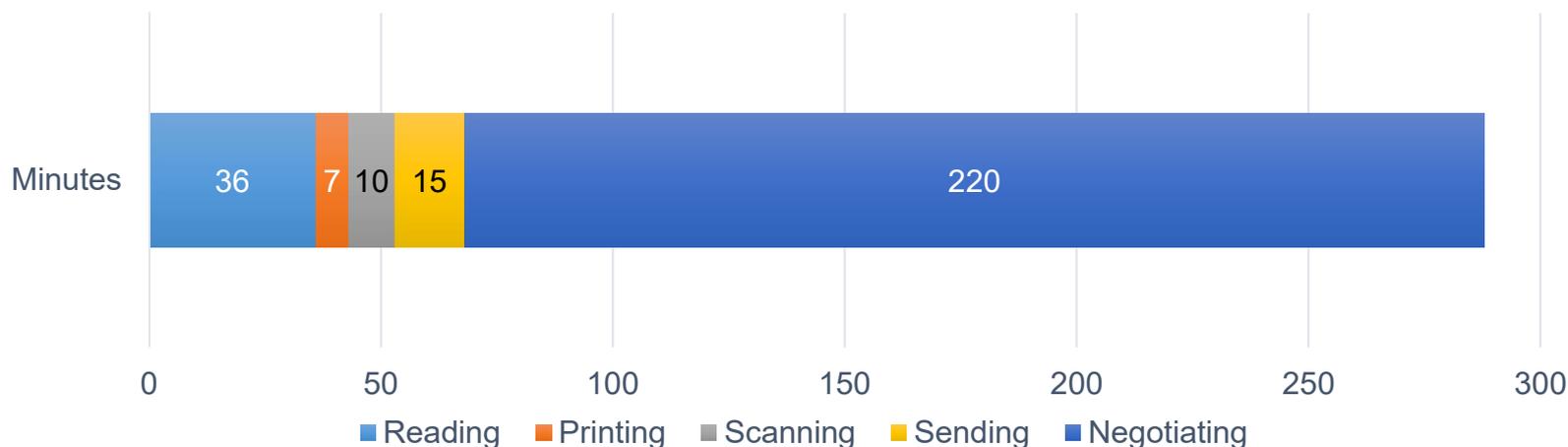
Why this initiative?

- **Collaboration between pharma and patient advocates requires us to sign contracts**, e.g. speaker agreements, consultancy or collaboration contracts
- **The contracts are often too long and difficult to understand**, and contain ambiguous clauses or terms that are in conflict with the nature of patient advocacy
- **Survey on “Reasonable agreements between patient advocacy and the pharmaceutical industry”** received responses by more than 80 patient advocates

Main issues in legal agreements

- The contracts provided to patient advocates are often too long and are difficult to understand
- 81% said all contracts are unreasonably extensive in length (6 pages or more, 19% even said they usually get contracts with more than 10 pages)
- Patient advocates invest on average 295 minutes (almost 5 hours) into reading negotiating and processing each contract

How much time (in minutes) do you usually invest for each agreement?



What's the problem?

Reasonable agreements vs. current agreements



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➤ **Current agreements:**

- Unilateral
- Disproportionate
- Blind signing and implicit coercion
- Too long
- Too complex
- Protect only industry & put patient advocates in a vulnerable position
- Use a template that does not reflect the contractual relationship well



➤ **Reasonable agreements:**

- Bilateral
- Proportionate
- Signed on the basis of informed and free consent
- Protects the interests of both parties
- Reflects the true nature of the contractual relationship
- Understandable to both parties



Main issues in legal agreements

- Consultancy agreement
- Collaboration agreement
- Advisory board agreement
- Community speaker agreement

Some problematic clauses and their key points:



Confidentiality



Intellectual property



Data protection



Compensation

- The agreements usually protect the company, making all content discussed within the collaboration or consultation confidential.
- Nothing should stop POs from doing their advocacy work, e.g. providing information to patients.
- Company receives exclusive rights to consultancy work provided by POs.
- Sometimes these clauses grants companies the worldwide and perpetual right to freely use any and all contents of a presentation done by the POs.
- Owner of data can object, access and request correction or deletion of their personal data at any time.
- If disclosure is required to achieve project objectives, the clause often does not state clearly which data and why.
- Honorarium or compensation for patient advocate's time, effort and knowledge needs is often not fair and reasonable, taking into account the level of expertise as well as preparatory or travel time.

Main issues in legal agreements



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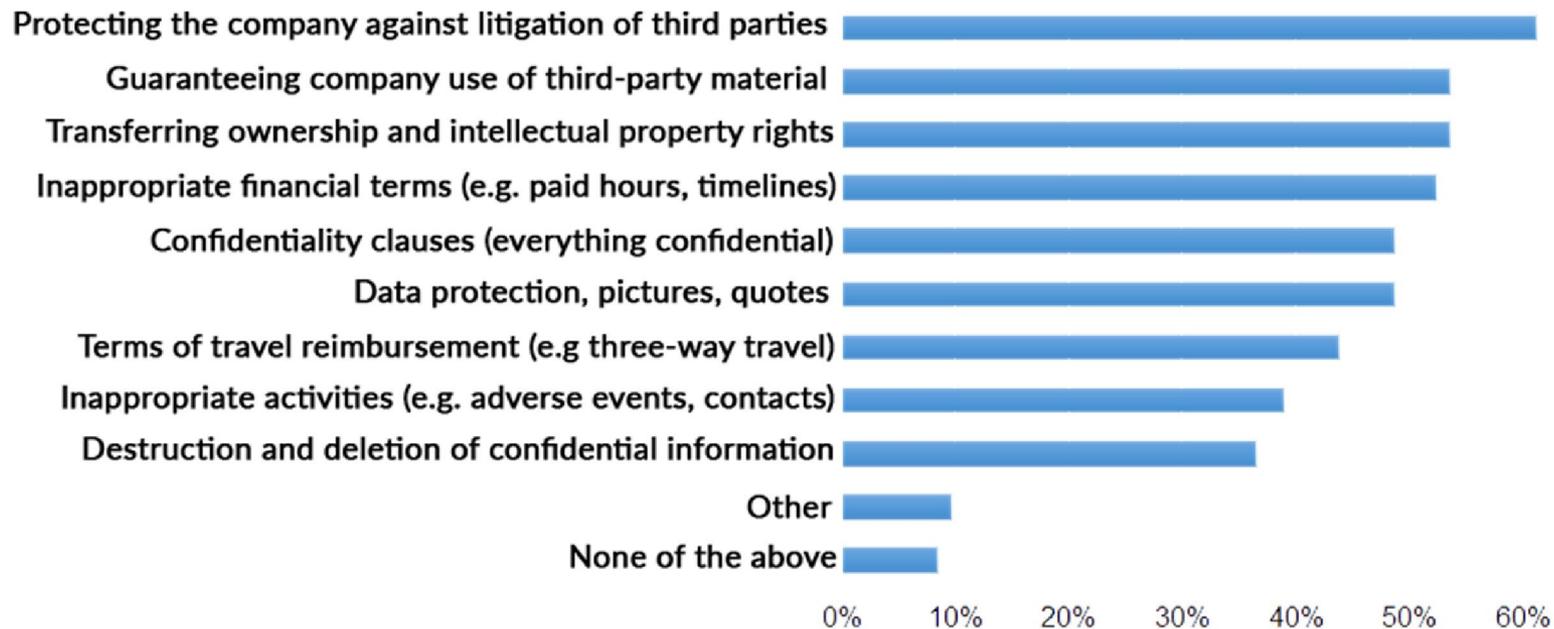


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The contracts provided to patient advocates contain ambiguous clauses or terms that are in conflict with the very nature of patient advocacy.

Which clauses in legal agreements do you usually find unreasonable?



Source: WECAN survey "Reasonable agreements between patient advocacy and the pharmaceutical industry", WECAN (2016)

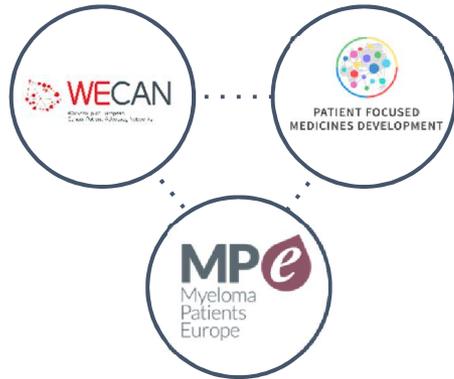
Reasonable legal agreements between patient advocates and pharmaceutical industry:

Next steps

RAPP project: Who is involved at this stage?



Drafting group



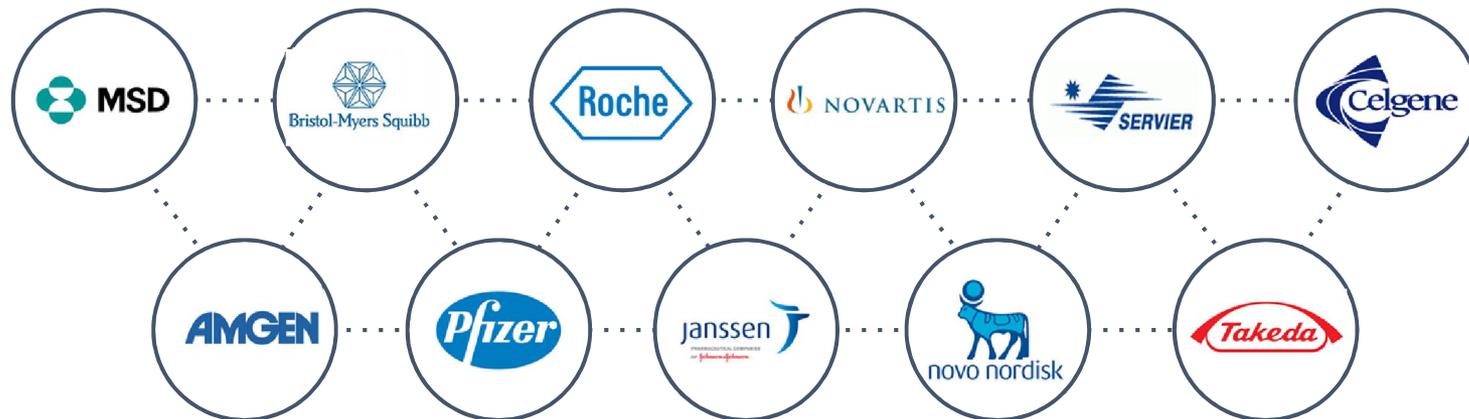
An external lawyer



3 pharmaceutical companies' representatives on behalf of the MSAW



Multi-stakeholder Alignment Workgroup (MSAW)



Structure and sections of Guiding Principles



Overall principles (main goals of the guiding principles)

- Section 1 – Confidentiality
- Section 2 – Intellectual property
- Section 3 – Recordings of meetings
- Section 4 – Data protection and use of personal data
- Section 5 – Indemnification, remedies and conflict resolution
- Section 6 – Compensation and reimbursements of expenses
- Section 7 – Adverse event reporting
- Section 8 – Independence and conflict of interest
- Section 9 – Glossary

All sections have 3 different parts:
“Rationale”,
“Examples”
and “Guiding principles”

Structure and sections of Guiding Principles



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Guiding Principles



- **First draft of the guiding principles document is finalised**, based on comments by advocates and company representatives
 - Around 10 teleconferences held to date to discuss the more conflictive clauses and suggested modifications
- The final revision of the document and the last teleconferences to discuss the new suggestions are scheduled for **May 2018**
- Then **Template Contract and Toolbox development** will start in **July 2018**



Questions?

Šarūnas Narbutas
sarunas.narbutas@pola.lt