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PID Principles of care Towards a PID life index

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Contents

1. Background: beyond the principles of Care
2. Towards a PID life index
3. Speedy interactive session: towards a PID life index

1- Background : beyond the principles of Care

Patient organisations need more and more to:

- raise awareness on PIDs,
- advocate for access to early diagnosis and efficient treatment
- know about their environment : neighbouring countries, globally!

As advanced diagnosis facilities, advanced treatment can't be considered at a single country scale.

2-Towards new tools: a PID life index

- **What is an index?**
 - “A sign or measure of something”
- Is this possible to measure a “life with PID”?

Why would a PID life index be helpful?

- The data from the PoC survey are crucial to:
 - provide a good understanding of how PIDs are considered and addressed in each country.
 - compare a country with another based on a set of different criteria.
 - provide data to benchmark the PID environment in one country to comparable countries and build arguments for advocacy campaigns (ie status of access to IG therapies, NBS, presence of specialist centres, etc) .
 - provide support to individual patients and their doctors and support the travel needs of PID patients from a country to another.

Why would a PID life index be helpful?

- Build a robust database linked to:
 - The 6 Principles of care
 - Other general data
- And then process it using data visualisation technology to present a comprehensive image of every country

The OECD Better life index

OECD: Organisation for Economic Co-operation and Development



	Housing
	Income
	Jobs
	Community
	Education
	Environment
	Civic Engagement
	Health
	Life Satisfaction
	Safety
	Work-Life Balance

Demo ...



The PID life index



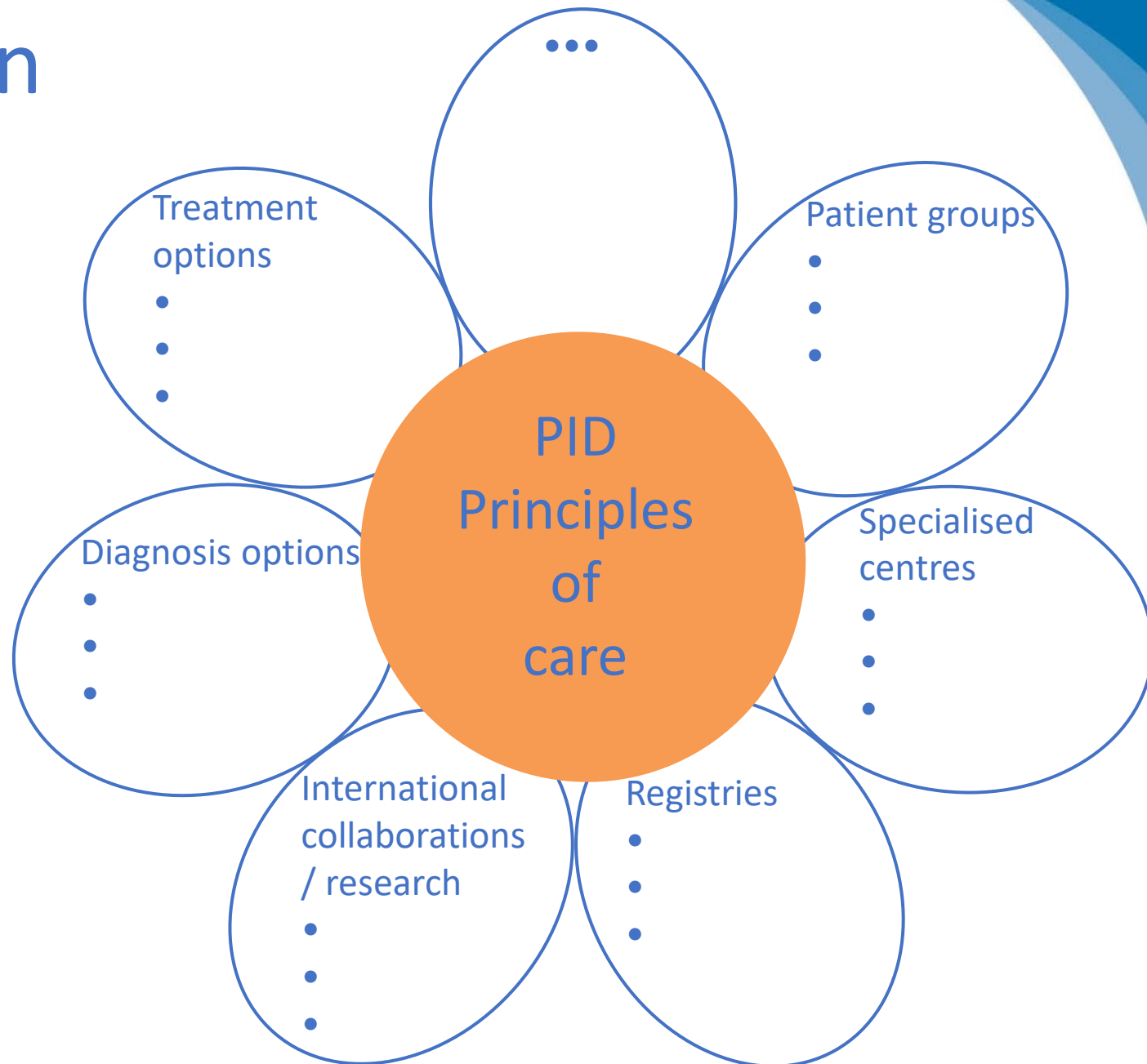
Specialised centres
Registries
International collaborations for scientific research
Patient groups
Treatment options
Diagnosis options
...

3-Now comes the question:

What matters most
to persons with PID
around the world?

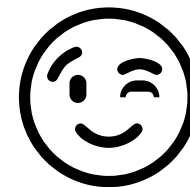
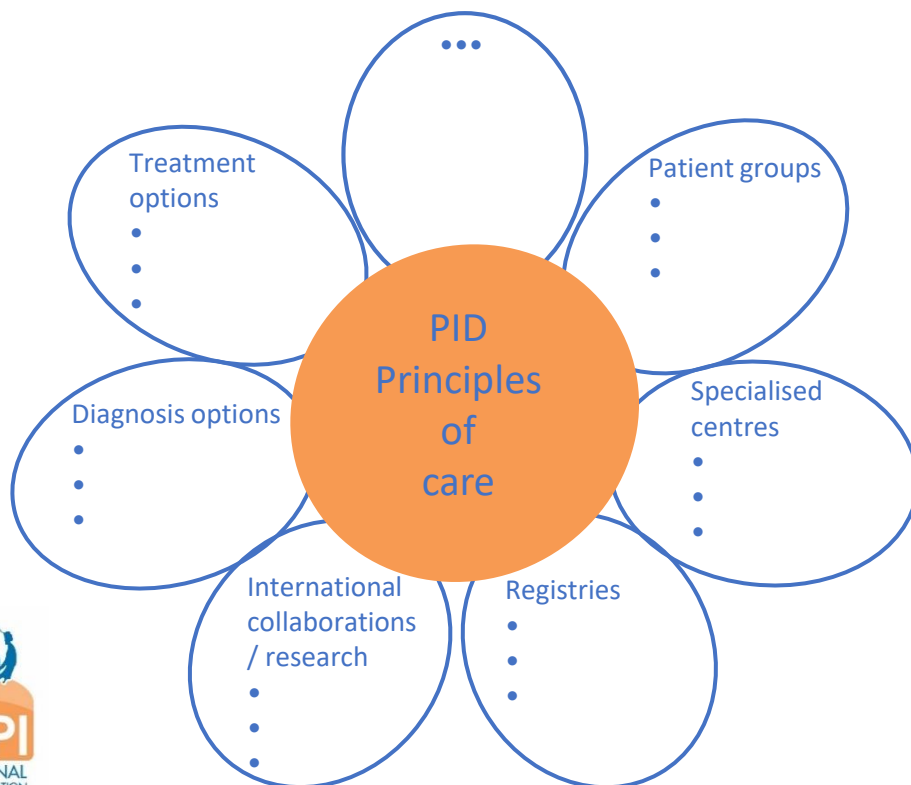
> Speedy interactive session

Towards a PID life index: >definition



Towards a PID life index >action

1- Gather with your neighbours and answer the question :
What matters to us as a persons/relatives with a PID?



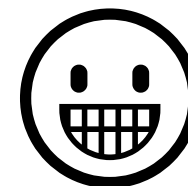
>Please be concise:
1 criteria = 1 word or 2

>Add petals if needed

Towards a PID life index

> Report back

Let's hear your suggestions



Specialised centres	X X
Registries	X X
Intern. Collaborations / scientific research	X X
Patient groups	X X
Treatment options	X X
Diagnosis options	X X
X	X X

Towards a PID life index

>share: **#PIDlifeindex**

>Take a picture of your group with the flowers and share this [in your language](#) on your national social media



Hey, I am at IPOPI meeting,
I am asked this question:
**“What matters to you
as a person with a PID?”**
What would you answer?

> Share the answers with us when you get them (mention your country!)

Conclusion

- We gave a first start to this PID life index
 - It would be a useful tool to:
 - Describe and understand how living with a PID looks like depending on the different criteria and countries
 - Benchmark and advocate
 - Engage NMOs, stakeholders and eventually even patients
 - It could be a model for other rare conditions
- We need to think of it further, for sure ...

Conclusion

- Please share the answers you'll get from your national fellows
- Thank you for your input



- If you are interested in this discussion, let us know!

Thank you!

#PIDLIFEINDEX

