What next?

PERSPECTIVES ON PANS

Vicky Burford
CEO, PANS PANDAS UK

Our Vision

"A brighter future for everyone affected by PANS and PANDAS"

Our Mission

Our mission is to ensure that everyone in the UK affected by PANS and PANDAS receives effective and equitable care. We will achieve this by supporting individuals and families, influencing policy and improving understanding through our work in community, healthcare, and education.

Our Values

Our values guide our strategy and our actions, they are at the heart of everything we do.

Integrity	Acting with honesty, trustworthiness and care
Compassion	Understanding and valuing lived experience
Community	Listening to and being guided by the community
Collaboration	Working together internally and externally
Empowerment	Providing robust information and raising awareness
Respect	Treating all people with dignity

[1] All Party Parliamentary Group
[2] Department of Health and Social Care
[3] National Health Service
[4] Department for Education

Devolved Nations: We aim to work equally across all four UK nations. Where we refer to DHSC, DfE or Local Authorities, we will engage with the relevant equivalent in each devolved nation

Our Strategic Priorities

Healthcare

We will advocate for effective and equitable healthcare by:

- Influencing national policy via the APPG[1] and DHSC[2]
- Developing a clinical guideline
- Collaborating with NHS[3] bodies, research groups and policymakers
- Supporting studies and data collection to strengthen evidence

Community

We will ensure no one affected by PANS or PANDAS feels alone by:

- Providing peer support via in person and online events
- Providing high quality, accessible information
- Working closely with our Youth Board ensuring their voices are heard
- Using surveys, feedback and community groups to stay responsive

Education

We will support educational systems to meet the needs of affected children by:

- Influencing education policy via the APPG and DfE[4]
- Providing Local Authority guidelines
- Training teachers, school nurses and educational psychologists
- Developing and distributing toolkits and resources for schools

Supporting studies and data collection to strengthen evidence

- RCPCH treatment guideline
- Local Authority Practice Principles
- Cost of Disease Burden Analysis
- All Party Parliamentary Group Lived Experience Report
- PANS PANDAS Unveiled
- Surveillance Study

Developing a clinical guideline

2

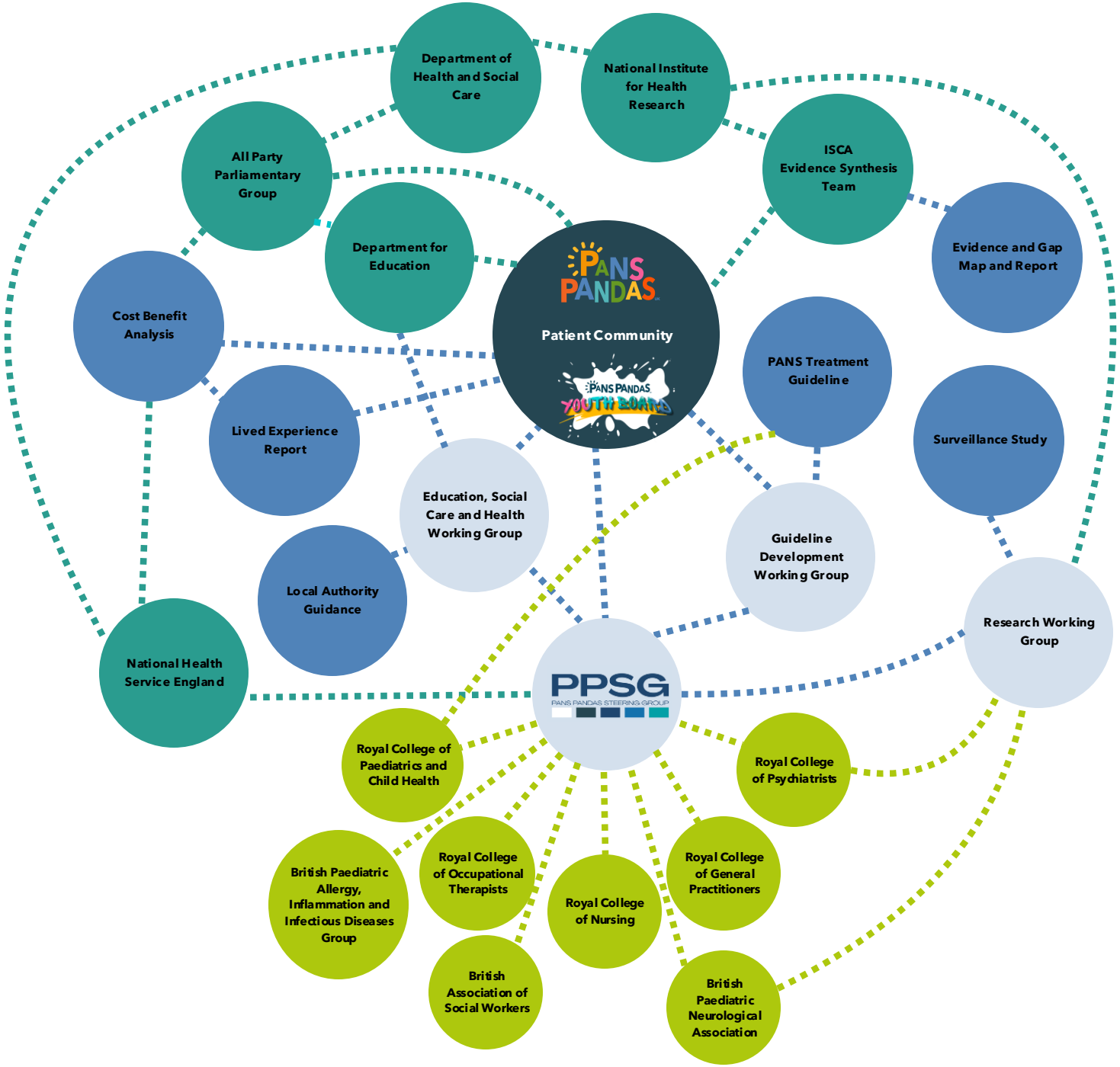
- Publication of treatment guideline with RCPCH
- Dissemination of guideline
- GP and CAMHS awareness campaign
- Training modules for healthcare professionals

Publication of Local Authority Guidance

3

- Publication of LA professional practice principles
- Dissemination of practice principles
- Local Authority Pilot
- Expansion of teacher training programme for allied healthcare professionals

Strategic Partnerships Mind Map



- Stakeholders represented within the PPSG
- PANS PANDAS Steering Group and Subgroups
- Outputs
- Stakeholder Collaborations

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Looking ahead three years, what should be our highest priority as a charity?

If PANS PANDAS UK could achieve just one major change for famililes over the next five years, what would it be?

How would you like to help shape our next strategy?

