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ABOUT EPILEPSY

Taken from Epilepsy: A Public Health Imperative, WHO 2019

BURDEN

The burden of epilepsy is high and often neglected in public health agendas. Epilepsy is one of the most common neurological diseases, affecting nearly 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health and social care needs and lost productivity at work.



STIGMA AND DISCRIMINATION

In all parts of the world, people with epilepsy are the target of discrimination and human rights violations. The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion. Improving knowledge and raising awareness of epilepsy in schools, workplaces, and communities is needed to reduce stigma. Legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.



BUT... IT IS TREATABLE

Three-quarters of people living with epilepsy in low-income countries do not get the treatment they need. Yet, up to 70% of people with epilepsy could become seizure free with appropriate use of cost-effective antiseizure medicines. A significant proportion of the burden of epilepsy could be avoided by scaling up routine availability of antiseizure medicines, possible at an annual cost as low as US\$5 per person. It is feasible to integrate epilepsy treatment into primary health care – training non-specialist providers, investing in continuous supplies of antiseizure medicines and strengthening health systems can substantially reduce the epilepsy treatment gap.



AND... IT IS PREVENTABLE

An estimated 25% of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.



ABOUT IBE

The IBE was established in 1961 and has grown to almost 150 chapters in over 100 countries all around the globe – an international network with real regional depth.

As the only voice for people with epilepsy worldwide, IBE has over 60 years of expertise in the areas of advocacy, information and education.

Therefore, IBE plays a leading role in tackling the burden of epilepsy worldwide – as outlined on Page 4. However, our focus is on addressing the most pressing needs of those people already living with epilepsy, and those who care for them. Our VISION is:

A transformational social change for people with epilepsy worldwide

But, as an international organisation, we need to optimise our position to advocate at the highest level and ensure our chapters are equipped to do so locally: So, it is our ASPIRATION to:

Advocate globally for epilepsy, and to support service provision locally by empowering organisations and advocates worldwide

This work is directed by our organisational VALUES which are to be:

- PEOPLE CENTRED
- INCLUSIVE AND COLLABORATIVE
- ACCOUNTABLE AND SUSTAINABLE
- IMPACT ORIENTED



OUR HISTORY

WHERE IT ALL STARTED...

A proposal is made by Dr Abraham Mosovich (Argentina), at the 9th International League Against Epilepsy [ILAE] meeting in Rome, to establish an office concerned specifically with the psycho-social aspects of epilepsy. This proposal leads to the creation of the International Bureau for Epilepsy [IBE].

Since then, IBE has worked with ILAE on joint regional and international epilepsy congresses, workshops, symposia and other meetings, as a means of increasing knowledge, awareness, understanding and acceptance of epilepsy, thereby improving services and quality of life for people with epilepsy and their caregivers.

THE EARLY DAYS...

The first issue of International Epilepsy News is published - it still runs today, over 200 editions later.

IBE President, Ellen Grass, introduces the Ambassador for **Epilepsy Awards** to honour those individuals who had made exceptional contributions to the field of epilepsy. Since then, the awards have been presented by IBE/ILAE to close to 400 recipients.

MORE RECENT YEARS...

The ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows' was launched in Dublin, during the 22nd International Epilepsy Congress, and at the WHO office in Geneva.

Global Campaign Against Epilepsy, Demonstration Project launched at WHO in Geneva. The campaign ran until 2009. The aim was to reduce the treatment gap and projects took place in Africa, Asia and South America. The most successful of these took place in China and led to the establishment of an epilepsy programme by the Chinese government aimed at managing convulsive forms of epilepsy at primary healthcare level.

Promising Strategies Program launched to meet IBE's commitment to support solutions to problems affecting people with epilepsy in developing nations. More than US\$400,000 has been provided to close to 100 projects in

IBE is given Special Consultative Status on the Economic and Social Council of the United Nations. This allows IBE to contribute to the programs and goals of the United Nations by serving as experts, advisers and consultants to governments and to the Secretariat.

IBE wins two important awards for Action Zone! an educational board game on epilepsy. The game won the Best International Public Relations Campaign Award and Communiqué Campaign of the Year. More than 40,000 units of the game were distributed worldwide.

THE LAST DECADE...

European Union Written Declaration on Epilepsy is approved with the signatures of 497 Members of the European Parliament.

International Epilepsy Day is launched and replaces European Epilepsy

WHO Resolution 68.20 on the Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications is approved by the World Health Assembly in Geneva.

EpilepsyNEXT becomes IBE's first major youth-focused initiative, comprising a number of elements including Youth Summits at regional/international congresses and the Golden Light Awards.

IBE Teams Initiative is launched, covering the areas of: Youth, Research, Academy and Professional Development. This built on earlier Commissions and Task Forces covering themes such as Driving, Employment, Insurance, Travel, Education, and Psychosocial Aspects such as stigma and discrimination.

TODAY...

WHO Resolution 73.10 on Global actions on epilepsy and other neurological disorders leads to a 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders which should provide a framework for actions on epilepsy worldwide for the next decade...

almost 40 countries around the world.











PROCESS

Process to develop the IBE strategic plan

Letter from IBE President, 2021-2026, Dr Francesca Sofia

Dear Friends,

I am pleased to share some background on the IBE Strategic Plan 2022-2026.

This Plan is, in fact, the result of a process of extensive analysis and consultation which was initiated by the new IBE management committee prior to taking office, and continued for several months, thereafter, with the involvement of the membership and other stakeholders.

We are very grateful to KPMG Australia for guiding and assisting us on this journey, which we felt was both necessary and urgent due to the unprecedented challenges facing the organization today.

The Covid-19 pandemic has shown us how precarious our very existence is and has profoundly changed social dynamics. In the meantime, health systems continue to face dwindling resources, rising costs and the impact of chronic diseases – while huge inequalities in access to care, discrimination and human rights violations still plague vast regions of the world.

Nevertheless, we have chosen to serve the epilepsy community with the confidence that, many times, opportunities are hidden in the challenges. Our strategic review process, which led to this plan, was based around uncovering such opportunities. As you will see in the following pages, there are many – with most arising from IBE's own capacity to bring people and organizations together and build a collective global voice for epilepsy.

The process officially began in May 2021 with a series of online, moderated plenary sessions of the IBE management committee, complemented by individual remote work. This took place over a period of two months to lay the foundations for a strategic proposition which the management committee, together with the new CEO, developed into a fully-fledged draft plan. In December 2021 this was presented to the IBE membership for consideration during an Extraordinary General Assembly. Surveys and further consultations with Vice-Presidents, Regional Executive Committees, individual chapters and other stakeholders followed, to add collective views – as well as specific insights – to the plan.

The outcome of this process is more than the document before you; it is a compass that will guide IBE towards a transformational social change so badly needed by people with epilepsy around the world. It is said that progress only occurs when people work together towards a common goal.

Therefore, I have no doubt that this plan is achievable because it is rooted in the commitment, synergy and shared purpose of our members and stakeholders.

What we identified...

STRENGTHS

IBE has been in existence for over 60 years, building up long-standing expertise and experience in the field. We are the only international organisation that wholly represents the voice of people with epilepsy.

IBE has a global reach – with regional depth, ensuring a presence in over 100 countries worldwide. This allows us to support poorly resourced chapters in lower and middle income settings, as well as engaging with richly resourced chapters in high income settings – creating a diverse and inclusive structure.

IBE's visibility and credibility is emphasised by the fact that we enjoy official working relations with the World Health Organisation and United Nations General Assembly, as well as a unique, collaborative partnership with our medical counterpart: The International League Against Epilepsy.

WEAKNESSES

However, despite IBE's good reputation amongst external stakeholders, internal governance and operational structures limit our ability to leverage core strengths. Currently, there are insufficient human and financial resources to implement an ambitious workplan. A diversified funding stream to support comprehensive and consistent workplanning is currently not in place. This has led to fragmented programmatic activity – with a lack of impact data to inform ongoing priorities.

As the organisation has evolved over the past 60 years, the governance structures have become complex and overly bureaucratic, stifling our ability to be disruptive and agile. IBE also currently sees too little involvement by people with epilepsy and their care providers, particularly in our hierarchy.

THREATS

And, there are a number of obstacles to addressing the weaknesses identified above. This includes competition for global funds from better resourced organisations, who may purport

to also serve the needs of people with epilepsy internationally.

Many language and cultural barriers – which in some cases are growing – make engagement a challenge between IBE and its chapters worldwide. Striking a balance between serving and supporting large chapters in high income settings, who may question the added-value of IBE, and small chapters in LMICs, is a major obstacle to be addressed.

Today, policy and decision-makers are also inclined to bundle individual diseases – such as epilepsy – into bigger buckets such as neurological disorders and/or non-communicable diseases, and – occasionally, and more problematically – in the lines of mental health.

OPPORTUNITIES

But, THE TIME IS NOW FOR EPILEPSY... the 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders will provide a framework for action worldwide, in which epilepsy is acknowledged as a strategic priority in its own right – as well as a clear entry point for action on other neurological disorders.

This is coming at a time where the growing importance of the lived experience is proliferating all areas – from policy making, to research and innovation, to healthcare service delivery and beyond...

And, in the epilepsy community, we have many committed advocates – and would-be advocates – who are eager to get involved, particularly young people with epilepsy who have been so active in volunteering as part of our Youth Team.

As we emerge from the Covid-19 pandemic, we are also seeing the acceleration of the digital transformation of healthcare – bringing new opportunities for how people with epilepsy are diagnosed, managed and treated, but also generating innovative approaches for IBE to reach and engage with our community.

IBE's strategy must take advantage of these opportunities – and in the coming pages you will learn how this will be implemented and monitored in the next 5 years.

Overarching 10-year goal



80%
of people diagnosed with
epilepsy with access to
appropriate, affordable,
safe antiseizure
medicines



STRATEGY

At a glance...

Impact Goals

Position epilepsy as a global public health priority

Empower and amplify the voice of people with epilepsy

Serve and support our chapters and committees in all regions

Strategic Action Areas

ADVOCACY AND AWARNESS RAISING

KNOWLEDGE CREATION AND EXCHANGE

CAPACITY BUIDLING

PARTNERSHIP DEVELOPMENT

Keynote
Initiatives &
Impact
Outcomes

GLOBAL ACTION PLAN

Scale up best practice – See positive progress vs. benchmarked patient-relevant IGAP targets – Develop advocacy tools – Strengthen strategic advocacy partnerships – Leverage International Epilepsy Day



IBE KNOWLEDGE HUB

Implement capacity development programmes – Build diverse pool of empowered global epilepsy advocates – Run research studies in at least 3 distinct areas – See yearly growth in knowledge hub use/engagement



GLOBAL EPILEPSY FUND

See annual IBE revenue growth -Ringfence funds for advocacy actions, linked to the IGAP, at national, regional and global levels

Strategic Support Structures

REVIEWING GOVERNANCE IMPROVING
ORGANISATIONAL
EFFECTIVENESS,
EFFICIENCY AND
SUSTAINABILITY

FUNDRAISING DRIVE

ENGAGING AND
OPTIMISING
MEMBERSHIP
INCL. SUB-GROUPS

MONITORING AND EVALUATING OUTCOMES

GOALS

Our overarching 10-year outcome goal:



At IBE, we advocate for a 90-80-70 cascade target to inspire a decade of action to achieve meaningful improvements in care and treatment for the 50 million plus people who live with epilepsy globally. This means having:

- 90% of all people with epilepsy aware of their diagnosis as a treatable brain disorder
- 80% of people diagnosed with epilepsy with access to appropriate, affordable, safe antiseizure medicines
- 70% of people with epilepsy on treatment achieve adequate seizure control

This strategic plan is part of a two phase approach (2 x 5 year strategic plans in the next 10 years) to position IBE as a key player in efforts to reach this target. Over the next five, IBE will work to put the groundwork in place for this overarching target, to be achieved by:

POSITIONING EPILEPSY AS A GLOBAL PUBLIC HEALTH PRIORITY

Since its foundation, IBE has been advocating for epilepsy to become a public health priority. This has culminated in the World Health Organisation's 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders [IGAP], 2022-2031. IBE now needs to focus on ensuring that this IGAP is implemented in every region of the world, with epilepsy at its core.

EMPOWERING AND AMPLIFYING THE VOICE OF PEOPLE WITH EPILEPSY

As an organisation purporting to be the global voice of people with epilepsy, IBE needs to build a diverse pool of people with epilepsy – and their representatives/advocates – worldwide. This group must then by equipped and empowered to engage in activities from research and innovation, to policy and decision-making – ensuring that such work is directed by their lived experience, needs and perspectives. However, we also need to make these opportunities more readily available to those we represent.

SERVING AND SUPPORTING OUR CHAPTERS AND COMMITTEES IN ALL REGIONS

IBE's commitment to advocacy, is matched by its commitment to service: serving our chapters in all parts of world. Our aim is to build the capacity of our chapters, providing them with the tools they need to directly serve the needs of people with epilepsy in their nation/region. We wish to see IBE's global efforts leveraged locally in the creation of concrete solutions with impactful outcomes for people with epilepsy wherever in the world they live.

STRATEGIC ACTION AREAS

To achieve the outcomes outlined in the previous section, we plan to work across four strategic action areas, as follows:

ADVOCACY AND AWARNESS RAISING

Awareness is the foundation of advocacy, which – in turn – paves the way to action! If we are to make epilepsy a global public health priority, we need to ensure that we continue to raise awareness of the burden of epilepsy globally; using the evidence that has been generated by the community over many years. However, we now need to look beyond communicating burden – focussing on promoting solutions that can be scaled up/implemented to address this; convincing governments around the world to take action now with tangible initiatives.

KNOWLEDGE CREATION AND EXCHANGE

However, for advocacy to be effective, it needs to be evidence-based. At IBE, we feel it is paramount that we are generating our own, 'patient' relevant data – to be added to the pool of existing evidence emanating from other sources/stakeholders. We are, though, committed to disseminating all information in an understandable manner to our community; empowering chapters and people with epilepsy. We must also better perform our role as a central convenor of the community by creating platforms for mentoring, peer to peer learning and information sharing.

CAPACITY-BUILDING

IBE is committed to building the capacity of our chapters – and that of individuals with epilepsy – by sharing knowledge and building skills through the organisation of training and educational initiatives. We realise that operational supports must also be considered and we will strive to support chapters in all aspects of their service provision.

PARTNERSHIP DEVELOPMENT

In this globalised and networked world, the epilepsy community cannot afford to exist in its own silo. We need to ensure that epilepsy is central in broader international public health policy dialogues. Epilepsy can be an exemplar – leading the way in actions on neurological disorders and even, more broadly, in the field of non-communicable diseases, particularly in lower and middle income settings. With a 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders now on the table, we need to ensure that we are connected to these other sectors of society and build networks and partnerships to reflect this outward-looking approach.



KEYNOTE INITIATIVES

Over the coming 5 years, IBE will launch three major keynote initiatives – spanning the action areas outlined previously – to create a focussed work programme aiming to reach the outcomes already explained.

Each keynote initiative will be modular in nature and comprise of blocks of time-bound programmatic activities/projects linked to delivering on impact outcomes.



GLOBAL ACTION PLAN

The 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders [IGAP] will provide a framework for action worldwide, in which epilepsy is acknowledged as a strategic priority in its own right – as well as a clear entry point for action on other neurological disorders. Running from 2022 to 2031, IBE is eager to ensure we move from Plan to Action.

Therefore, in the five year time frame of this Strategic Plan, we will undertake a major advocacy and policy workstream.

At IBE we must select the most 'patient-relevant' targets within the IGAP, generate real-world baseline data from our community, and then monitor progress against these agreed benchmarks.

This will include a bi-annual survey, progress report and showcase event at high level political forums such as the World Health Assembly and/or United Nations General Assembly. Here we will also highlight best practice and scalable solutions.

In the intervening years, we will also conduct awareness/advocacy campaigns at the both global and regional levels, based on the learnings and recommendations from the progress report.

Of course, IBE will work closely with other stakeholders and partners on this advocacy, ensuring that our approach is aligned and complementary to the work being carried out elsewhere.

This work will require human resources in the form of advocacy/policy staff but also the identification and training of Epilepsy Ambassadors – building on work already underway as part of the Utetezi Project in the African Region, including the expansion of the African Advocates Toolkit, legislative mapping and training modules.

GLOBAL EPILEPSY FUND

IBE is aware that funding is a major obstacle to reaching the targets set out in the IGAP. Working with global philanthropic (and other) entities, we hope to build a global epilepsy fund which will support IBE, our regional committees and chapters – as well as external actors with common goals – to implement transformative projects and initiatives, with tangible deliverables.

Impact outcomes

Scale up cost-effective best practice models
– such as IBE's African Utetezi Project – to
accelerate the development and growth of a
sustainable epilepsy advocacy community in
other regions of the world, in order to influence
policy, legislation, financing, implementation
and accountability around epilepsy. At least two
other regions should see similar, coordinated
action in the coming 5 years.

Generate baseline data on patient-relevant targets in all regions – linked to the IGAP – and see positive progress against this benchmark over the five year time frame.

See **IBE revenue growth** each year over the coming five years, **ensuring ringfenced funds to support advocacy actions** of our chapters/committees – linked to the IGAP – **at national, regional and global levels.**

Develop and update publications, briefs and training tools on relevant and timely policy issues and emerging evidence, with a focus on the implementation gaps to support advocacy and accountability on the IGAP – surveying chapters on use and usefulness of such resources

Develop and strengthen strategic advocacy partnerships with key opinion leaders, scientific societies, research institutions, governments and other civil society groups to position epilepsy centrally in global public health policy dialogues – with at least one collaborative, multi-stakeholder activity/event annually.

Leverage International Epilepsy Day as a vehicle to advance advocacy and awareness raising for epilepsy – ensuring year on year growth in engagement metrics and reach over the coming five years.



KEYNOTE INITIATIVES continued

IBE KNOWLEDGE HUB

This knowledge hub will be an online and interactive IBE infrastructure aiming to increase chapter engagement, and build capacity amongst chapters and advocates worldwide.

It will encompass an e-learning academy which will be focussed on empowering and equipping advocates with the knowledge, skills and tools they need to position the voice of people with epilepsy in relevant forums, activities and processes e.g. research and development, scientific congresses/medical education, policy and decision making, healthcare service planning and delivery, etc.

It will also be a central point for conducting our own research studies but also disseminating the latest data in the field to our community in a understandable manner.

The interactivity will enable the sharing of resources and materials – particularly from chapters in high income regions to those in lower and middle income settings. The hub will also feature dedicated work/meeting space for our regional committees, teams, commissions and councils – but also for membership sub-groups who need/want a platform where they can interact ongoingly.

This approach should help to address the current programmatic fragmentation within IBE, bringing together the resources that have been developed over more than 60 years – in various regions – in one, accessible place. It will also ensure ongoing engagement and communication with our community in real-time.

Impact outcomes

Implement a portfolio of capacity development programmes and resources with, and for, IBE regional committees, chapters and people with epilepsy – including training programmes, tools and guidance documents, grants/small funds and peer to peer learning/mentoring – which are evaluated and rated highly by users.

Build a diverse pool of empowered global epilepsy advocates to strengthen the meaningful engagement of people with epilepsy in all relevant processes/initiatives, and work with external stakeholders/partners to create opportunities for such engagement – ensuring participation from all regions and demographics.

Coordinate research studies in at least 3 distinct areas – covering areas of identified unmet need – and resulting in resources for people with epilepsy that are translated, accessed and utilised by our chapters, with positive evaluation reports.

Ensure the **growth and sustainability** of the Knowledge Hub – with **year on year increase in numbers** taking part in training modules, accessing content and engaging in groups each year of this 5-year frame.

STRATEGIC SUPPORT STRUCTURES



REVIEWING GOVERNANCE

Over this strategic period, good governance will become a priority as it is key to achieving our mission and goals, and maintaining our credibility with current and new partners. At the centre of our governance are our chapters and, therefore, we need to create a framework that, ultimately, brings us closer to them – addressing their needs, and the needs of those they serve: people with epilepsy worldwide.



IMPROVING ORGANISATIONAL EFFECTIVENESS, EFFICIENCY AND SUSTAINABILITY

To achieve the impact goals outlined in this strategy, IBE will need to use its limited resources in an efficient and effective way. This includes a focus on securing both human and financial resources, whilst exploring how internal processes can be simplified and improved to lessen the administrative load, whilst generating more impactful output.

IBE will:

- Engage legal expertise to review the IBE constitution (and its associated by-laws, policies and procedures) – including consideration of optimal legal address/place of registration
- Strive for diversity and inclusivity in IBE's governance structure, including in leadership positions – ensuring people with epilepsy have an opportunity to play a meaningful role in determining IBE's strategic direction
- Ensure an accessible and transparent Annual General Meeting process, at least, every two years
- Expand our membership base, regularly survey/consult chapters on priorities and needs, and enhance platforms for membership engagement and coordination

IBE will:

- Hire additional staff to lead work in identified strategic action areas
- Conduct an internal organisational mapping exercise with the aim of streamlining Committees, Commissions, Taskforces and Teams – eliminating redundancy and ensuring alignment with strategic plan
- Conduct an external mapping exercise with the aim of prioritising IBE involvement in partners activities in alignment with strategic plan
- Support chapters in promoting the sustainability of IBE
- Fundraise (see below)



FUNDRAISING DRIVE

Traditionally, IBE was sustained by congress income. However, as IBE's activities move away from focussing on scientific congresses to implementing a programme of work which brings most added value to our target audience – our chapters and people with epilepsy worldwide – new and ongoing revenue streams must be identified and pursued. It is essential that we have a secure source of income annually to support programmatic activity but, also, coverage of core costs.



ENGAGING AND OPTIMISING MEMBERSHIP AND ITS SUB-GROUPS

IBE's strength is in the organisations and people at its core. However, we recognise that the IBE chapters and those living with epilepsy are not a homogenous group. Within the organisation there are also specific sub-groups who may have specific unmet needs that require special attention. For example: chapters/people in lower and middle income settings, women with epilepsy, young people with epilepsy, and those living with/working on rare epilepsies. We need to ensure that we have channels to facilitate the amplification of these voices, and opportunities for their meaningful engagement in our work.



MONITORING AND EVALUATING OUTCOMES

We believe it is important to measure the impact outcomes of our activities, particularly if we wish to engage new partners, secure new revenue streams and convince chapters of IBE's added value. We will strive, not only to measure performance, but also to ensure we report/disseminate these findings and embed learnings in our work moving forward.

IBE will:

- Convene a Corporate Council composed of industry partners
- Produce annual project proposals linked to the workplan – with associated sponsorship packages
- Map global philanthropic entities working in areas of mutual interest, linked to the proposed Global Epilepsy Fund
- Evaluate how new IBE initiatives could be monetised
- Review membership dues structure

IBE will:

- Convene a Consumer Council composed of a diverse mix of people with epilepsy and their caregivers, to be consulted ongoingly on IBE's internal and external work programme
- Appoint an Engagement Manager to ongoingly support involvement of people with epilepsy in internal and external activities
- Through the IBE knowledge hub, ensure a focus on areas of identified unmet needs by running research studies, providing capacity building opportunities and creating a platform for exchange

IBE will:

- Conduct a mid-term review of this strategic plan in 2024
- Conduct an annual review with each team member
- Run a yearly self-evaluation process amongst the Management Committee and International Executive Committee members (to gather insights on collective and individual performance)
- Ensure each project proposal includes an agreed evaluation framework
- Include progress tracker and clear metrics in the annual report
- Commission an independent strategy review in 2026 to evaluate performance and impact and inform the next strategic period (2027-2031).





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