Assessing the impact of the specialist workforce on care of children and young people with epilepsy

Epilepsy12 and OPEN UK conference

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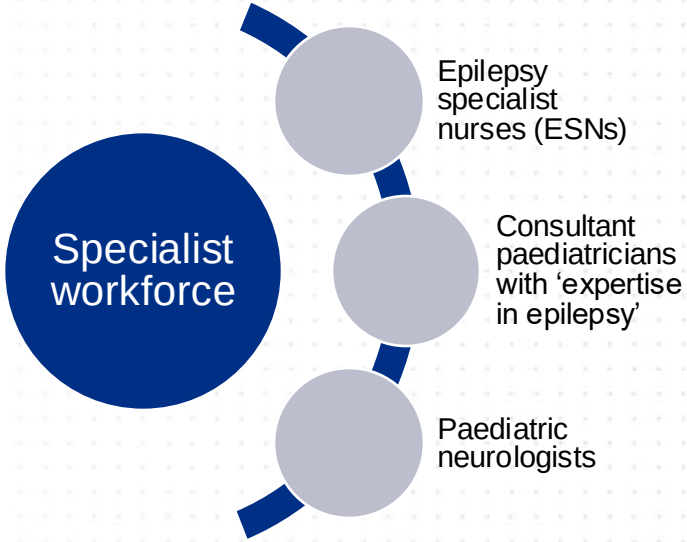
Today

- **Project commissioned by NHS England to assess impact of specialist workforce**



- Specialist workforce chosen, as it was highlighted, by stakeholders, that:

The level and mix of specialist staff can affect the care and treatment of CYP with epilepsy and health care system resource use and efficiency

There is a shortage

Today

- Approach
- Key findings and recommendations
- Evaluation framework

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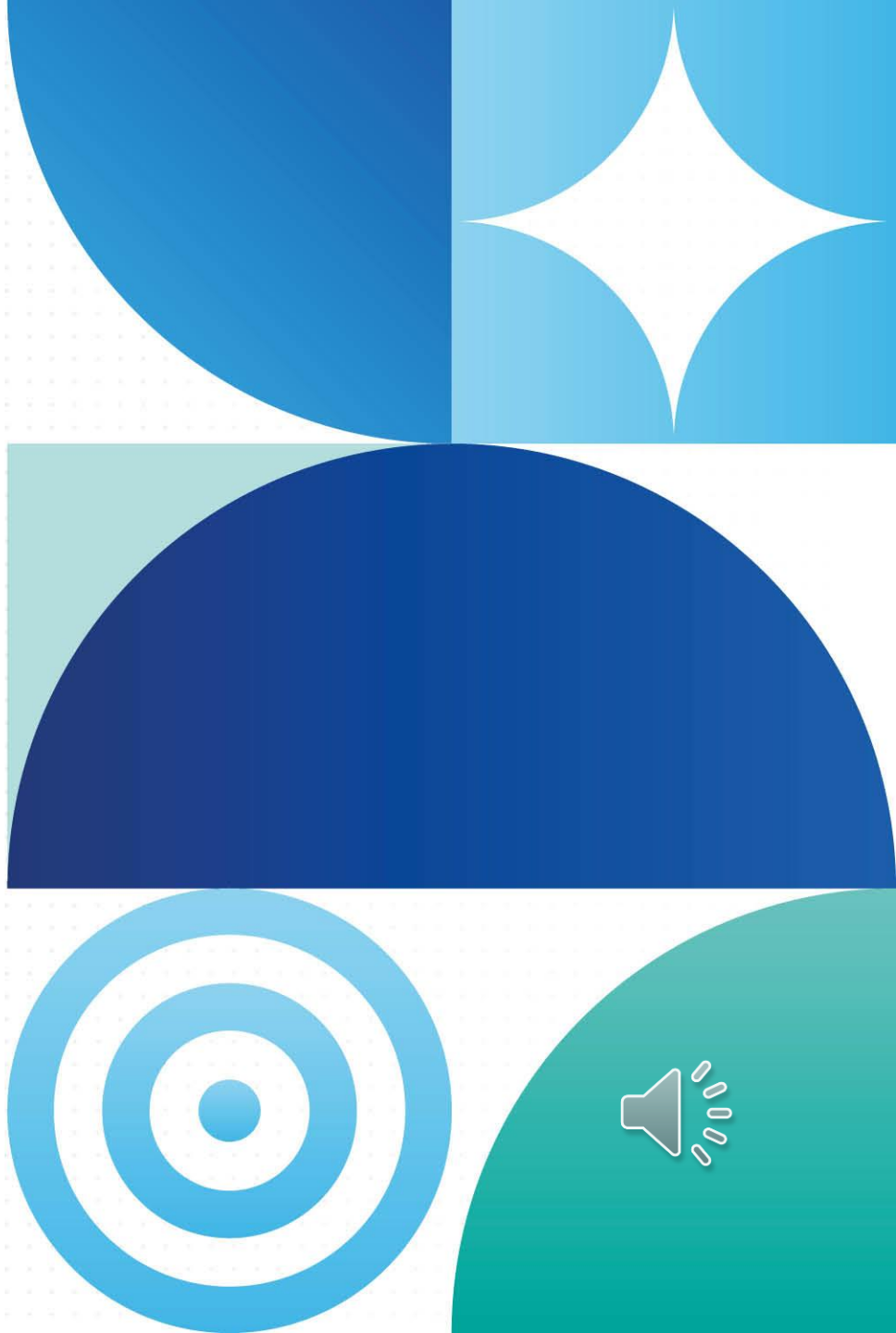
Approach



Mixed-methods approach

Two stakeholder workshops

- Shortlisting and exploring important areas of the care pathway:
  - Particularly around the specialist workforce and the expected impact of care

Literature review

- Reviewing previous research into the effect of specialist workforce on clinical and resource use outcomes

Analysis of health datasets (Epilepsy12 data)

- Identifying relationships within real-world data to understand how the specialist workforce may impact care of CYP with epilepsy.
- Examples of analysed impact include assessing evidence of care planning, clinical reviews and rescue medication usage

Economic framework

- Producing a framework to allow providers to input their local data and comprehend the economic value of different interventions:
  - For example, comparing the costs and outcomes of an increase in workforce

Epilepsy12 data

Organisational audit collects service-level data on:

- Workforce
- Epilepsy clinic configurations
- Tertiary provision
- Investigations
- Care planning
- Young people and transition services
- Mental health provision
- Neurodevelopmental support
- Patient database/register

Clinical audit collects patient-level data on:

- Demographic information
- Diagnostic status
- Performance indicators
- Initial referral and examination
- Description of episodes
- Neurodisability and mental health problems
- Investigations
- Treatment
- Professionals and services involved in care

Approach to analysis

Exploratory analysis

- Understand data
- Assess completeness and data quality

Descriptive analysis

- Initially assess specialist workforce clinical care measures

Staff spend analysis

- Assess how clinical measures differ according to service level spend on specialist staff

Advanced analyses

- Use statistical and data science techniques to examine the relationship between specialist workforce and clinical care measures

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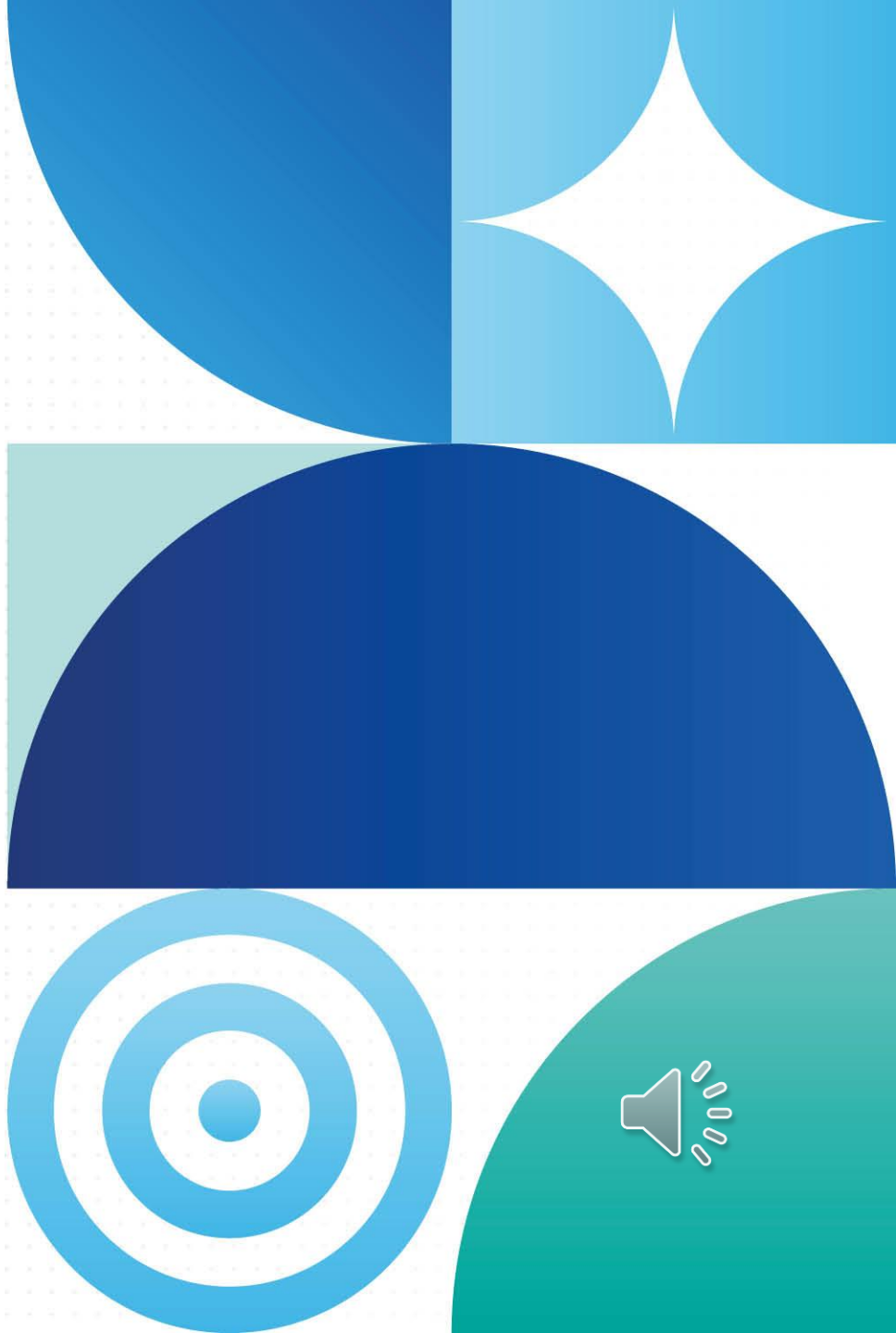
Key findings and recommendations



Key findings

Epilepsy specialist nurses can generate cost-savings to the NHS

Some CYP with epilepsy do not have access to specialist staff in their first year of care

Better access to ESNs is associated with better care planning, improved transition, and referrals to adult and mental health services

Better access to a consultant with ‘expertise in epilepsy’ is associated with better access to clinical review, defined epilepsy clinics and mental health referral pathways

Health Boards/Trusts staff services differently and it is difficult to discern the optimal mix of specialist staff

We provide recommendations around the limitations of analysis

Key findings - 1

Epilepsy specialist nurses can generate cost-savings to the NHS

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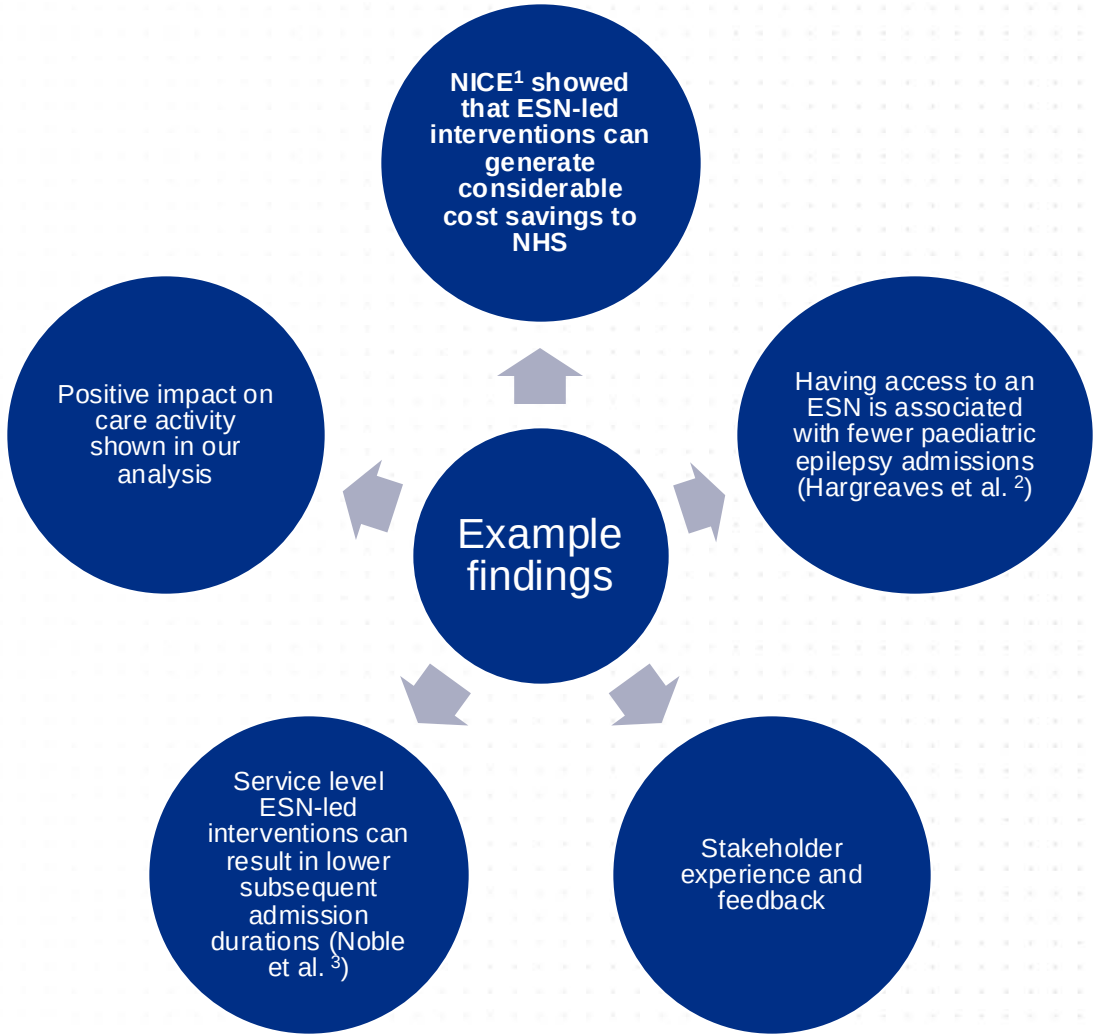
1. Epilepsy specialist nurses can generate cost-savings to the NHS



- **We recommend:**
  - Trusts and integrated care systems prioritise investment in ESN-led interventions to take advantage of the potential cost-savings.
  - Further research be performed to demonstrate the value of the specialist workforce, taking account of the full range of resource use, clinical, patient, and economic outcomes. The supplied framework can be used by local systems to support this aim.

Key findings - 2

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2. Some CYP with epilepsy do not have access to specialist staff in their first year of care

- **Specialist staff levels need to be sufficient to meet health need across all providers:**
  - 83.0% of CYP had access to an ESN in first year of care – access means input requested and achieved.
  - 89.1% of CYP had access to consultant paediatricians with 'expertise in epilepsy'.
  - 25.4% of CYP had access to paediatric neurologists – Not all CYP should have access as paediatric neurologists should be prioritising complex epilepsy, nonetheless evidence suggests there is still a gap.
- Access to specialist staff is highly correlated with WTE staffing levels.
- Acknowledge increasing staff is challenging, but research by Epilepsy Action (2023) [4] stresses shortage:
  - One neurologist to every 868 people with epilepsy.
  - One ESN to every 1,397 people with epilepsy.
  - Shortage more pronounced in some areas.

2. Some CYP with epilepsy do not have access to specialist staff in their first year of care

Recommendations

- **NHS England invest in the ESN workforce and ensure there is a sufficient supply of nurses to meet the needs of CYP with epilepsy** so that they do not miss out on important care elements, e.g. care planning, transition, and referrals to adult and mental health services

- **As indicated by stakeholder experience and feedback, providers should ensure that there is sufficient ESN staffing to provide comprehensive care planning for all CYP with epilepsy.** A ratio of 1 ESN per 250 CYP has been previously suggested, although further work to determine an effective ratio given varying levels of need should be undertaken

- **NHS England should invest in the Consultant Paediatrician with 'Expertise in Epilepsy' and Paediatric Neurologist workforce and ensure there are enough to meet the needs of CYP with epilepsy**, regardless of where they live. NHS England could consider incentives for increasing supply in areas where there is a clear mismatch between demand and supply

Key findings - 3

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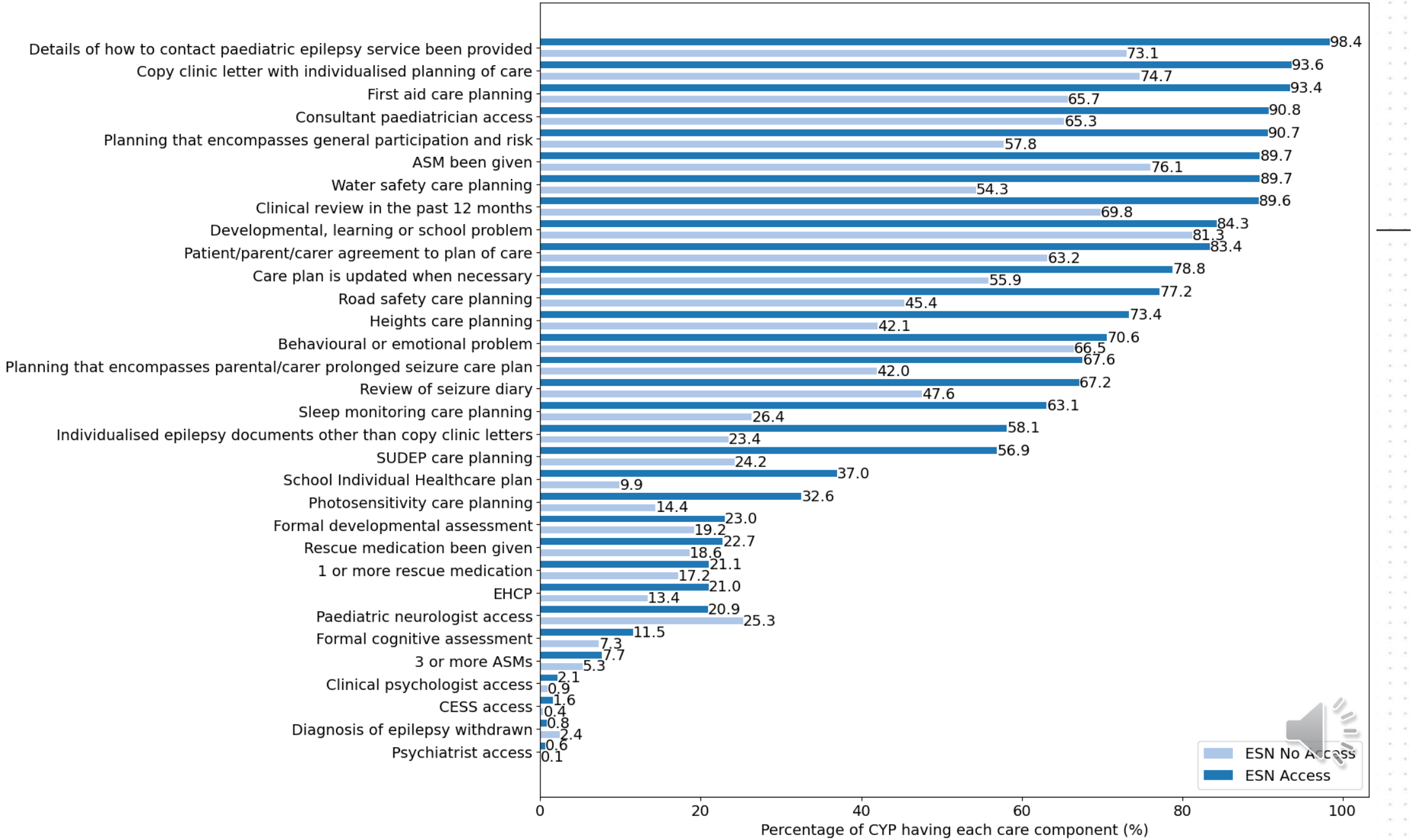
3. Better access to ESNs is associated with better care planning, improved transition, and referrals to adult and mental health services

ESNs

- **CYP with access to an ESN, compared to those who did not, were:**
  - **More likely to have evidence of various care planning activities: such as, sleep monitoring, clinic letters, and water safety, and specialist advice between reviews**
  - More likely to be receiving care in a health board/trust that has agreed referral pathways for children with mental health concerns.
  - More likely to be in health boards/trusts with a broader range of ESN functions being delivered, such as, school meetings, home visits, and nurse led clinics.
  - More likely to be receiving care in a health board/trust offering tertiary neurology referrals. Further research is needed to understand if this is due to patient need or service design and staff composition.

- Analysis highlighted benefit of an adult ESN in transition which was associated with a health board/trust having agreed referral pathways to adult services and/or outpatient clinics.


Details of how to contact paediatric epilepsy service been provided
Copy clinic letter with individualised planning of care
First aid care planning
Consultant paediatrician access
Planning that encompasses general participation and risk
ASM been given
Water safety care planning
Clinical review in the past 12 months
Developmental, learning or school problem
Patient/parent/carer agreement to plan of care
Care plan is updated when necessary
Road safety care planning
Heights care planning
Behavioural or emotional problem
Planning that encompasses parental/carer prolonged seizure care plan
Review of seizure diary
Sleep monitoring care planning
Individualised epilepsy documents other than copy clinic letters
SUDEP care planning
School Individual Healthcare plan
Photosensitivity care planning
Formal developmental assessment
Rescue medication been given
1 or more rescue medication
EHCP
Paediatric neurologist access
Formal cognitive assessment
3 or more ASMs
Clinical psychologist access
CESS access
Diagnosis of epilepsy withdrawn
Psychiatrist access
98.4
73.1
93.6
74.7
93.4
65.7
90.8
65.3
90.7
57.8
89.7
76.1
89.7
54.3
89.6
69.8
84.3
81.3
83.4
63.2
78.8
55.9
77.2
45.4
73.4
42.1
70.6
66.5
67.6
42.0
67.2
47.6
63.1
26.4
58.1
23.4
56.9
24.2
37.0
9.9
32.6
14.4
23.0
19.2
22.7
18.6
21.1
17.2
21.0
13.4
20.9
25.3
11.5
7.3
7.7
5.3
2.1
0.9
1.6
0.4
0.8
2.4
0.6
0.1
ESN No Access
ESN Access
0
20
40
60
80
100
Percentage of CYP having each care component (%)

3. Better access to ESNs is associated with better care planning, improved transition, and referrals to adult and mental health services

Recommendations

- **Trusts ensure they have sufficient WTE ESNs in post to ensure all CYP with epilepsy have access to ESN support so that they do not miss out on important elements of care**
- **Further research needed to understand how better access translates to other important outcomes**, such as, improved self-management of epilepsy, mental health diagnoses and treatment, and wider resource use in the health system
- Further research needed to understand to explore how inequity in access effects the care and treatment CYP with epilepsy receive, and health and care resource use and efficiency

Key findings - 4

Epilepsy specialist nurses can generate cost-savings to the NHS

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4. Better access to a consultant with ‘expertise in epilepsy’ is associated with better access to clinical review, defined epilepsy clinics and mental health referral pathways.

Consultants with ‘expertise in epilepsy’

- **CYP with epilepsy who have access to a consultant paediatrician with ‘expertise in epilepsy,’ compared to those who do not, were more likely:**
  - **To have a clinical review by a consultant paediatrician or paediatric neurologist.**
  - To have evidence of care planning activity, medications provided, formal cognitive assessment, and access to clinical psychologists
  - **To be receiving care at a health board/trust delivering defined epilepsy clinics.** This is important considering that one in five providers (19.5%) were not providing defined epilepsy clinics in 2021/22

- Health boards/trusts with higher levels of WTE consultants more likely to have referral pathways to mental health services in place

4. Better access to a consultant with ‘expertise in epilepsy’ is associated with better access to clinical review, defined epilepsy clinics and mental health referral pathways.

Recommendations

- **Trusts should ensure they employ enough WTE consultants with ‘expertise in epilepsy’ so that all CYP can access better care, such as care planning, access to clinical review, defined epilepsy clinics and mental health referral pathways**
- **Further research is needed to understand how better access translates to other important outcomes**, such as, improved self-management of epilepsy, mental health diagnoses and treatment, and wider resource use in the health system
- Further research is needed to explore how inequity in access effects the care and treatment of CYP with epilepsy and health and care resource use and efficiency

Key findings - 5

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5. Health Boards/Trusts staff their services differently and it is difficult to discern the optimal mix of specialist staff

Findings

- CYP with access to consultants with ‘expertise in epilepsy’ tend to have access to ESNs
- CYP with access to paediatric neurologists less likely to have access to consultants or ESNs
- Research suggests that CYP with access to a paediatric neurologist were more likely to have had rescue medication administered, more ASMs, formal developmental assessment and access to CESS - all indicators that this patient group have more complex care needs

Recommendations

- Further research to understand the substitution and complimentary nature of the specialist workforce and the effects of different models of care on the care and treatment of CYP, quality-of-life measures and the wider health care system

Key findings - 6

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6. Recommendations around limitations of analysis

Further research be performed using linked data

- Within CYP first year of care, linking activities relating to the specialist workforce in time
- Between Epilepsy12 and other datasets (SUS, HES, ECDS, Mortality, etc.)

Epilepsy12 outcome linkage

- Epilepsy12 should be funded to routinely collect clinical and resource outcomes across all health boards/trusts or NHS England should commission research of linked Epilepsy12

Other

- Future research should perform subgroup analysis analysing known inequality indicators
- Various other recommendations around data, guidance for evaluation, etc

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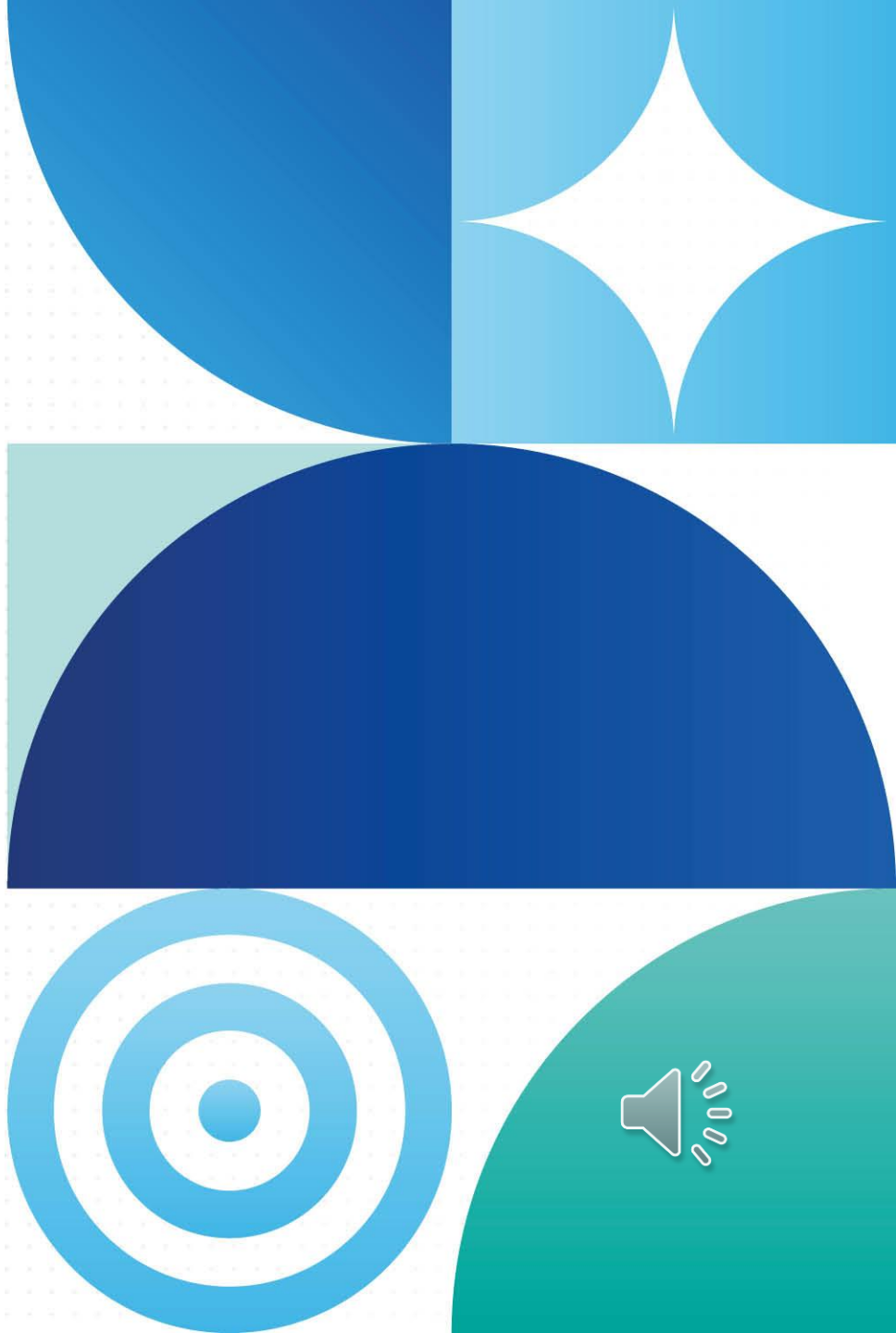
Economic framework user tool



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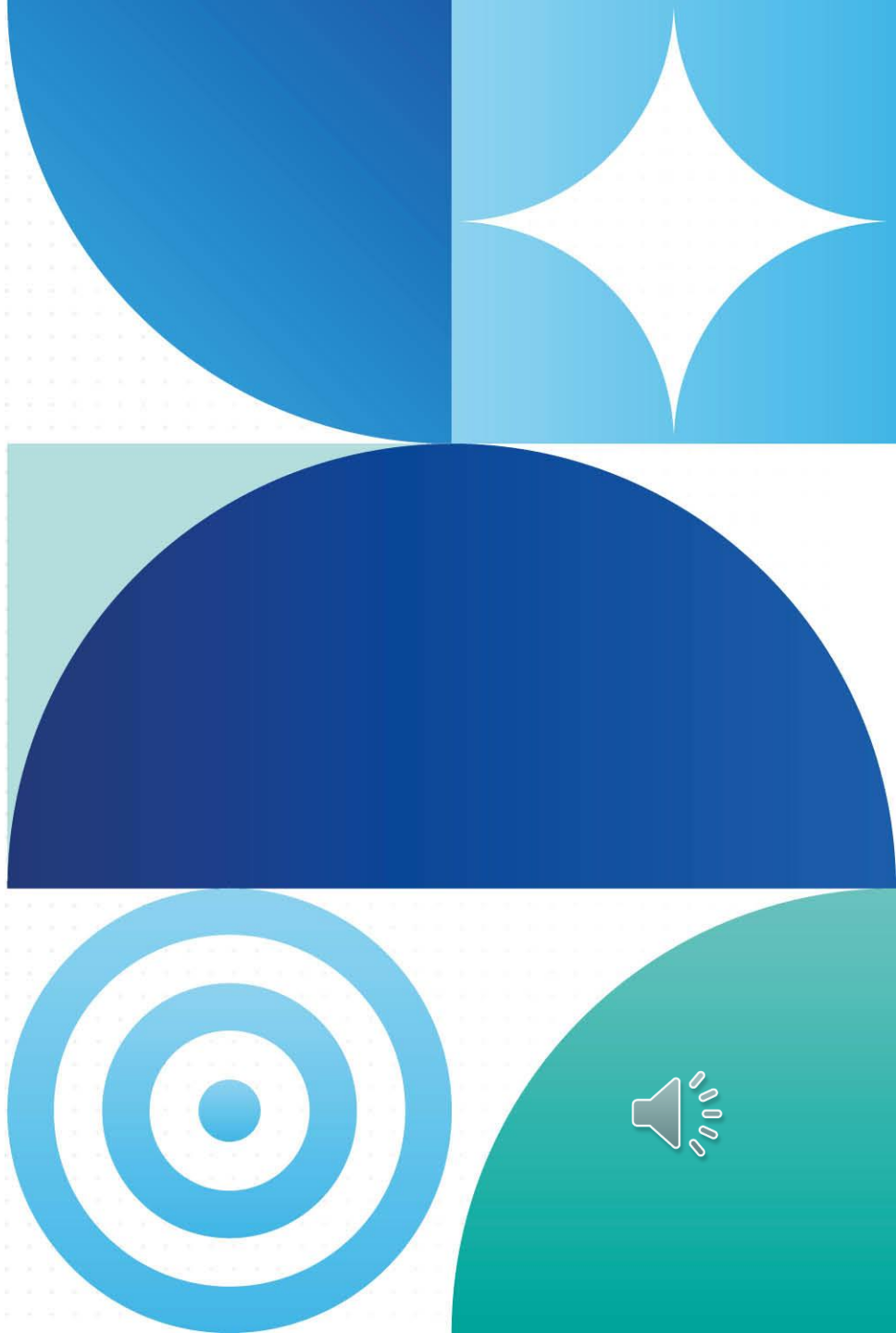
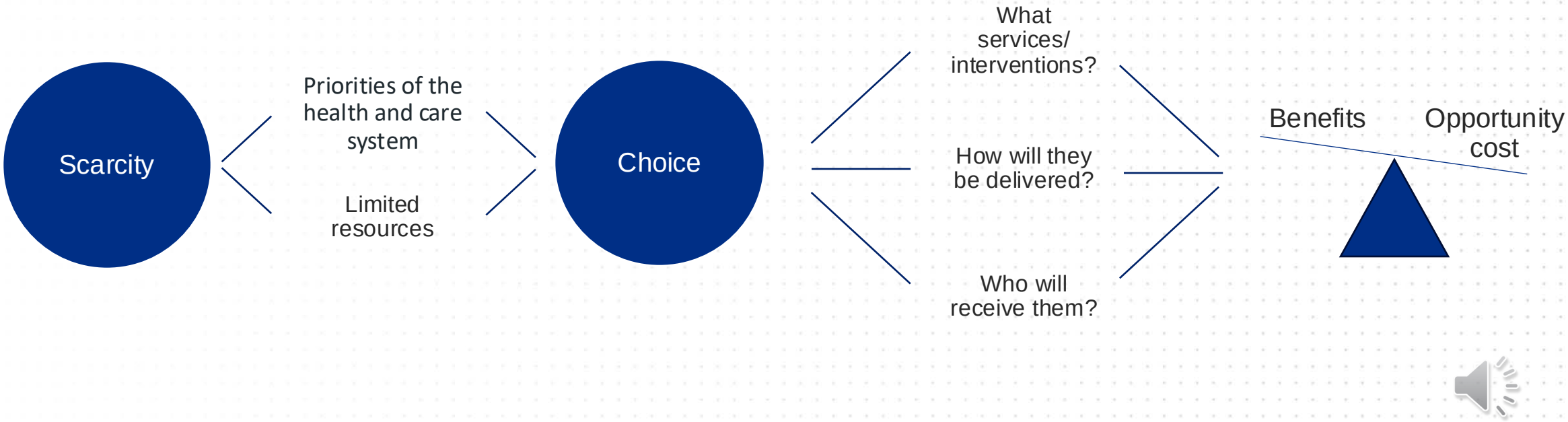


What is meant by ‘value for money’



Evaluation approach and methods will depend upon…

- Type of intervention (e.g. workforce change or introducing a new technology)
- Impact on the population (e.g. clinical risks)
- Financial risk to the payer (i.e. the cost or investment required)
- Decision making context/perspective (the setting/who will be paying)
- Outcome(s) of interest
- Available evidence and data
- Access to the right skills (analytics, economic analysis)
- Resources to deliver evaluation (time and budget)

Approach to evaluation

Define research Qs and decision problem

- Background research to understand the intervention
- Review existing info and evidence
- Define the intervention and comparator
- Define the population
- Determine perspective and decision-making context

Perspective

The perspective of an economic evaluation is the point of view adopted when deciding which costs and benefits are included in an evaluation.

At different levels and in different parts of the healthcare system decision makers have different priorities

- Mainly different budgets but also needs of local population

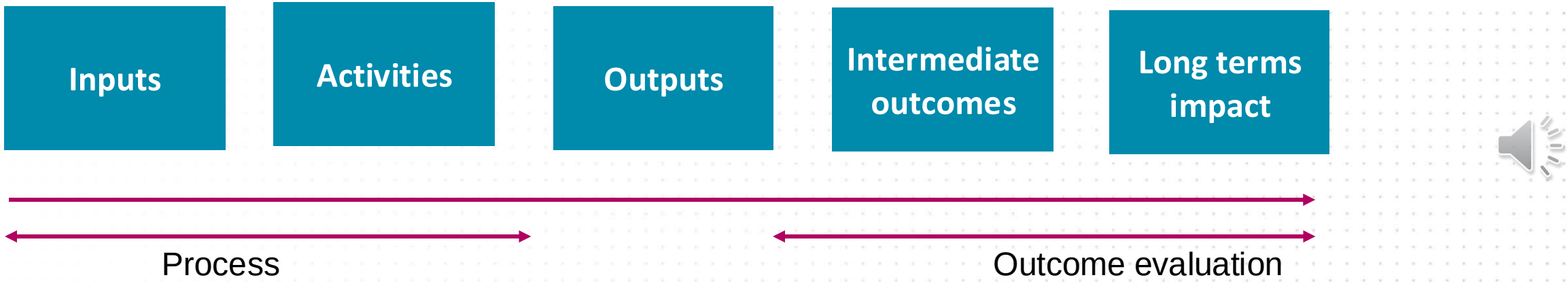
NICE: health and social care perspective

Identify and describe expected impacts

- Map out intervention and comparator pathways
- Theory of change exercise to understand expected impact and ensure relevant costs and benefits are considered
- Define outcome measure

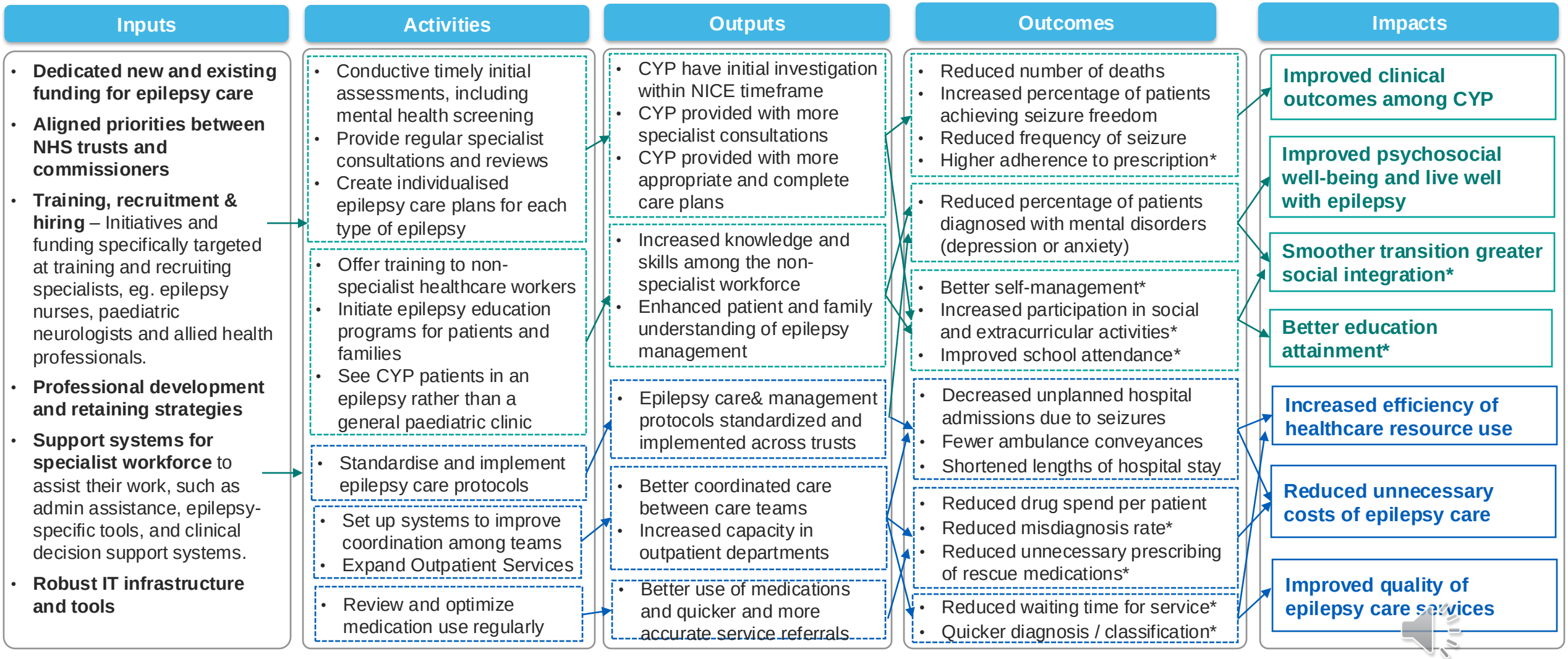
Logic model for evaluations

- **Inputs:** Resources necessary for program / intervention implementation
- **Activities:** What is being done during implementation in order to achieve outcomes
- **Outputs:** Direct products obtained as a result of program activities
- **Outcomes**: measurable outcomes or results of program implementation
- **Impacts:** The long-term impact



Rationale

- **Epilepsy requires targeted healthcare by specialists.** Epilepsy requires specialists care to reduce mortality risk and other challenges that CYP patients face.
- **Specialist workforce is well-positioned to deliver improved health outcome.** They work across teams, offer faster & more accurate diagnosis and empower patients.
- **Specialist workforce involvement could potentially be cost-saving for the NHS.** They could free up consultants' capacity, and reduce need to access emergency care.



Assumptions

- **Availability of Specialist Workforce.** There is a sufficient supply of qualified epilepsy specialists willing to work within the NHS.
- **Stakeholder Buy-in.** NHS trusts, commissioners, and other stakeholders are committed to the epilepsy care program and its objectives.
- **Continuity of Funding.** The dedicated funding for epilepsy care and specialist workforce initiatives will remain consistent over time.

Key

Patient perspective
NHS perspective
*** Limited data availability**

Decide evaluation approach

- Describe optimal approach to evaluation
- Decide study design

Evaluation types

Process evaluation

- Was the intervention delivered as intended?
- What worked well, for whom, why? Redesign
- What could be improved?

Impact evaluation

- Answers cause and effect question
- Did the intervention achieve the expected outcomes
- Are there any unintended outcomes?
- Are the outcomes produced by the intervention?
- Will the intervention work elsewhere? Generalisability

Value-for-money evaluation

- Compares the costs and benefits of the intervention
- Informs value for money decisions

Adapted from Stern (2015). Impact evaluation: a guide for commissioners and managers. Available at: https://assets.publishing.service.gov.uk/media/57a0896de5274a31e000009c/60899_Impact_Evaluation_Guide_0515.pdf
Accessed 1st November 2022

Types of economic evaluation

Approaches	Output to describe cost-effectiveness	Example Qs
Cost-utility analysis	Incremental cost-effectiveness ratio, cost per quality-adjusted life year	Which intervention is more cost-effective and affordable to the NHS?
Cost-effectiveness analysis	Incremental cost-effectiveness ratio e.g. cost per admission avoided	Which intervention reduces pressure on acute services for the lowest cost?
Cost-consequence analysis	Present costs and different categories of benefits separately	Which intervention offers the best combination of costs and outcomes?
Cost-benefit analysis	Assign monetary value to costs and benefits, present net monetary benefit	Which intervention maximises return on investment?
Budget impact analysis	Net budget impact	What is the budget impact to ICS of introducing intervention?

Types of economic evaluation

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Budget impact analysis	Net budget impact	What is the budget impact to ICS of introducing intervention?

Carry out evaluation

- Collate any additional data and evidence
- Carry out analysis and modelling (qual, quant, economic), including sensitivity analysis
- Develop tools e.g. cost calculator

Report and disseminate findings

- Report findings
- Develop business case

Links to resources to support evaluation and economic evaluation

- Medical Research Council A framework for developing and evaluating complex interventions: update of Medical Research Council guidance | The BMJ
- Magenta book HM Treasury guidance on what to consider when designing an evaluation https://www.gov.uk/government/publications/the-magenta-book
- NHS Evaluation Toolkit: https://nhsevaluationtoolkit.net/
- NHS Economic Evaluation Toolkit: https://nhsevaluationtoolkit.net/resources/economic-evaluation-guide/
- Strategy unit' guide to support high quality evaluation in the NHS: https://www.strategyunitwm.nhs.uk/news/free-guide-support-high-quality-evaluation-nhs
- WHOs, Monitoring and evaluating DHIs: 9789241511766-eng.pdf (who.int)

Acknowledgements - HEU

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- Amit Bali, Barts Health NHS Trust
- Anita Devlin, The Newcastle Upon Tyne Hospitals NHS Foundation Trust

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Thank you

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https://healtheconomicsunit.nhs.uk/

References

[1] National Institute for Health and Care Excellence. *Epilepsies in Children, Young People and Adults: [O] Effectiveness of a Nurse Specialist in the Management of Epilepsy. NICE Guideline NG217. Evidence Reviews Underpinning Recommendations 11.1.1-11.1.4 in the NICE Guideline*. (2022).

[2] Hargreaves, D. S. *et al.* Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. *Lancet Child Adolesc Health* **3**, 627–635 (2019).

[3] Noble, A. J., McCrone, P., Seed, P. T., Goldstein, L. H. & Ridsdale, L. Clinical- and Cost-Effectiveness of a Nurse Led Self-Management Intervention to Reduce Emergency Visits by People with Epilepsy. *PLoS One* **9**, e90789 (2014).

[4] Wood, G. Epilepsy specialist shortage a ‘crisis.’ The government’s latest NHS workforce plan failed to mention epilepsy or neurology. *Epilepsy Action* https://www.epilepsy.org.uk/epilepsy-specialist-shortage-a-crisis (2023).