



ML

A care system support
organisation



UNIVERSITY OF
PLYMOUTH
Peninsula Medical School

EPILEPSY
ACTION

Step Together

Creating capable communities to keep
people with epilepsy and a learning
disability safe

Tom Shillito, Epilepsy Action

Background

Step Together: Creating capable communities to keep people with epilepsy and a learning disability safe



Step Together Toolkit

Based on **Step Together guidance**

Coproduced with HCPs and PWELD and carers/families

Benchmarks against an ideal service, up to 100%

Domains covered:

- Workforce
- Local planning
- Key service provision
- Diversity of provision
- Care planning
- Information sharing
- Transition
- Service user and carer participation



Data Collection

17 ICB across England (1 did paediatric only so is excluded from this analysis)

Data collection from 2023- 2025

Stakeholders:

- Psychiatrists and neurologists
- Epilepsy and learning disability nurses
- Commissioners
- Primary care
- Local general hospitals
- Social care and residential care providers
- Service users, families and carers



Results

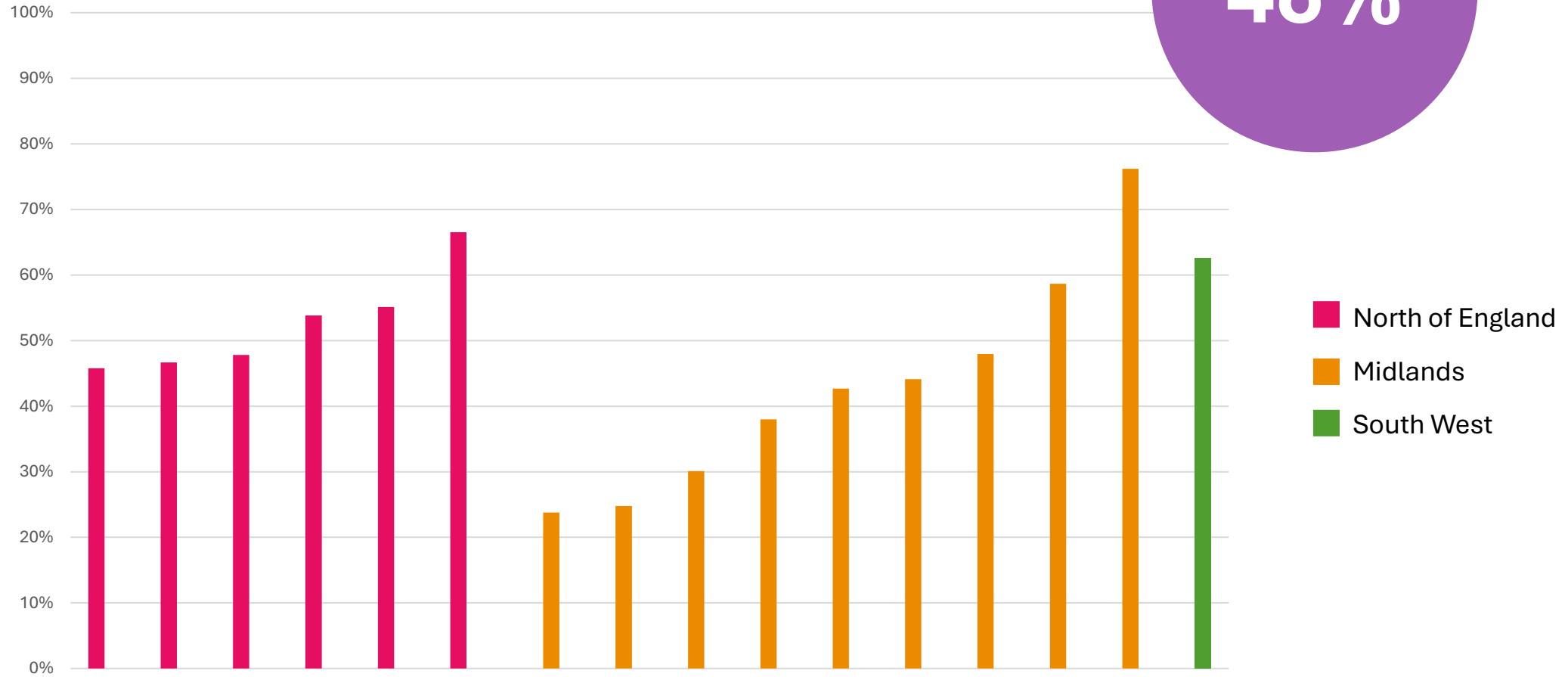
Step Together: Creating capable communities to keep people with epilepsy and a learning disability safe



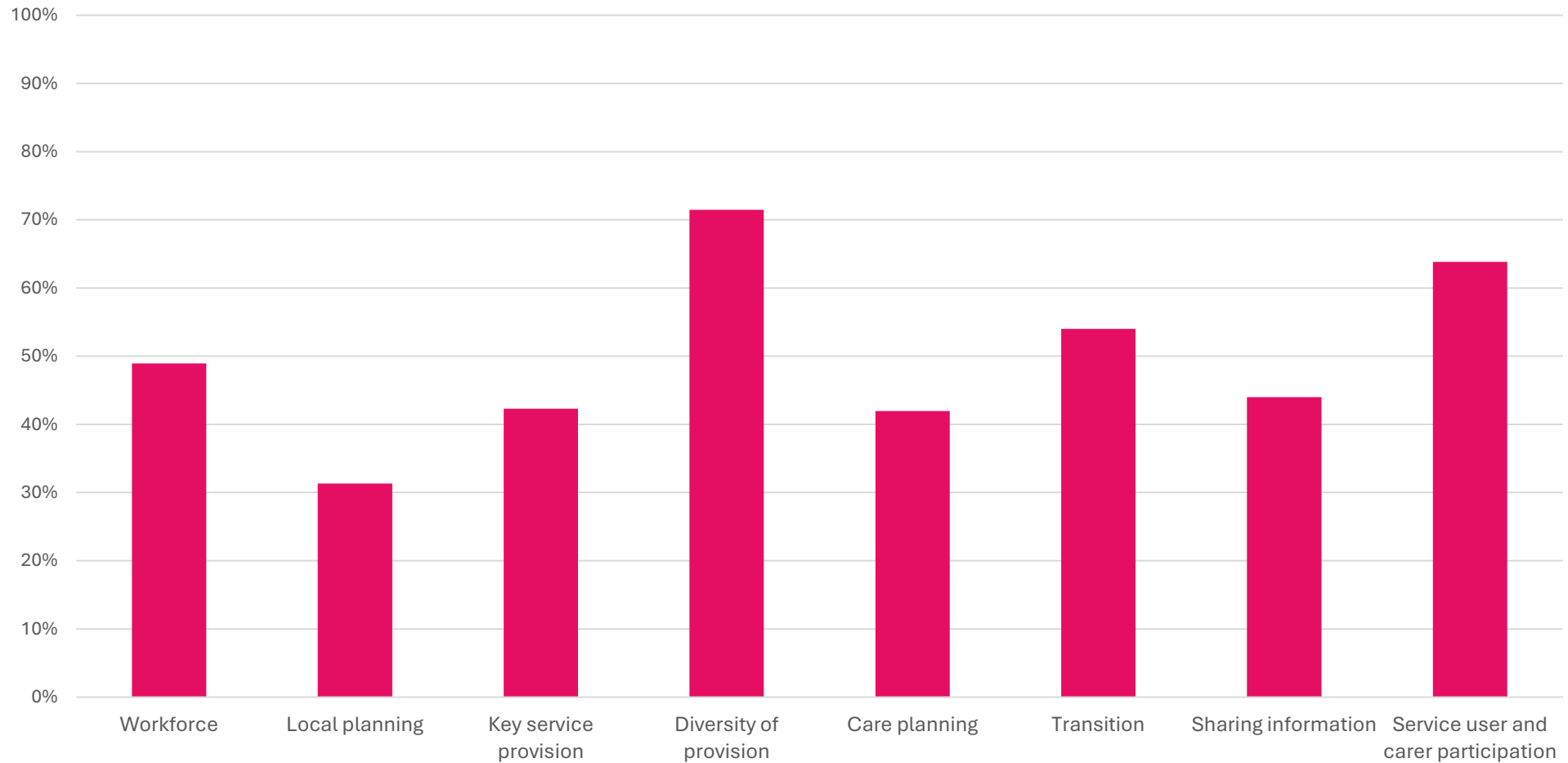
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Overall results- by ICB

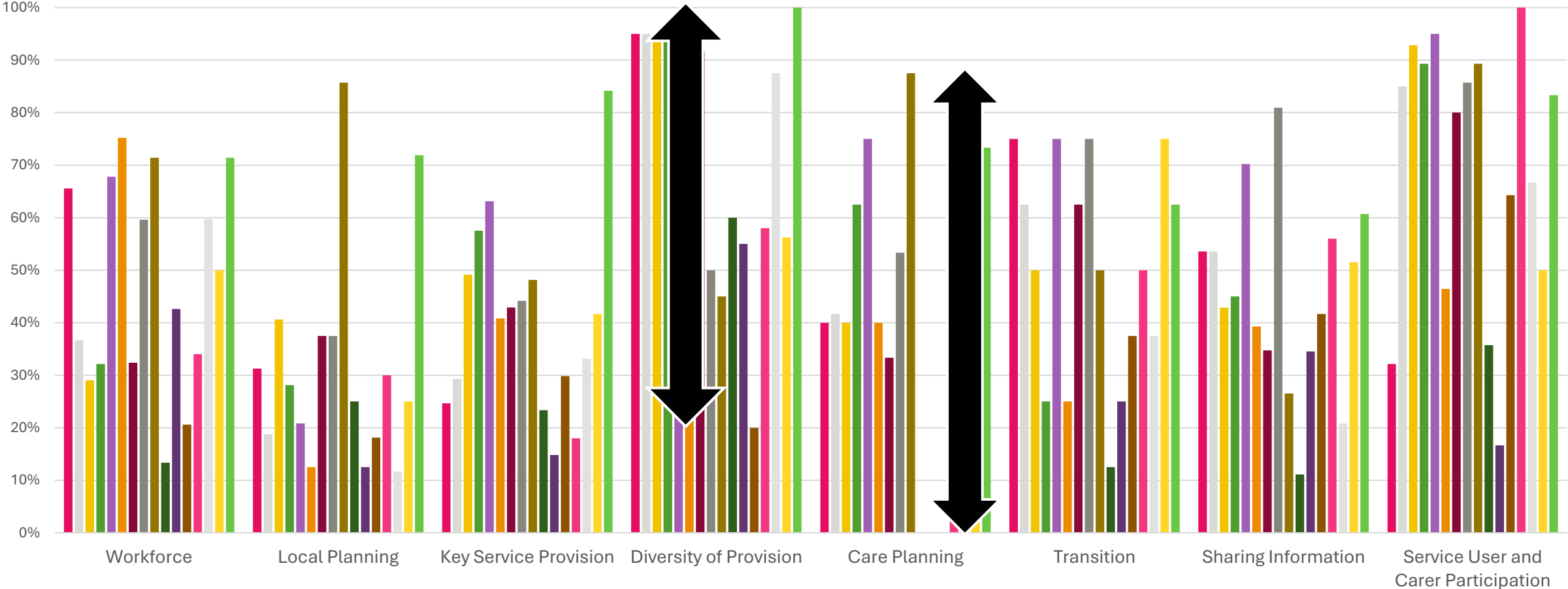
48%



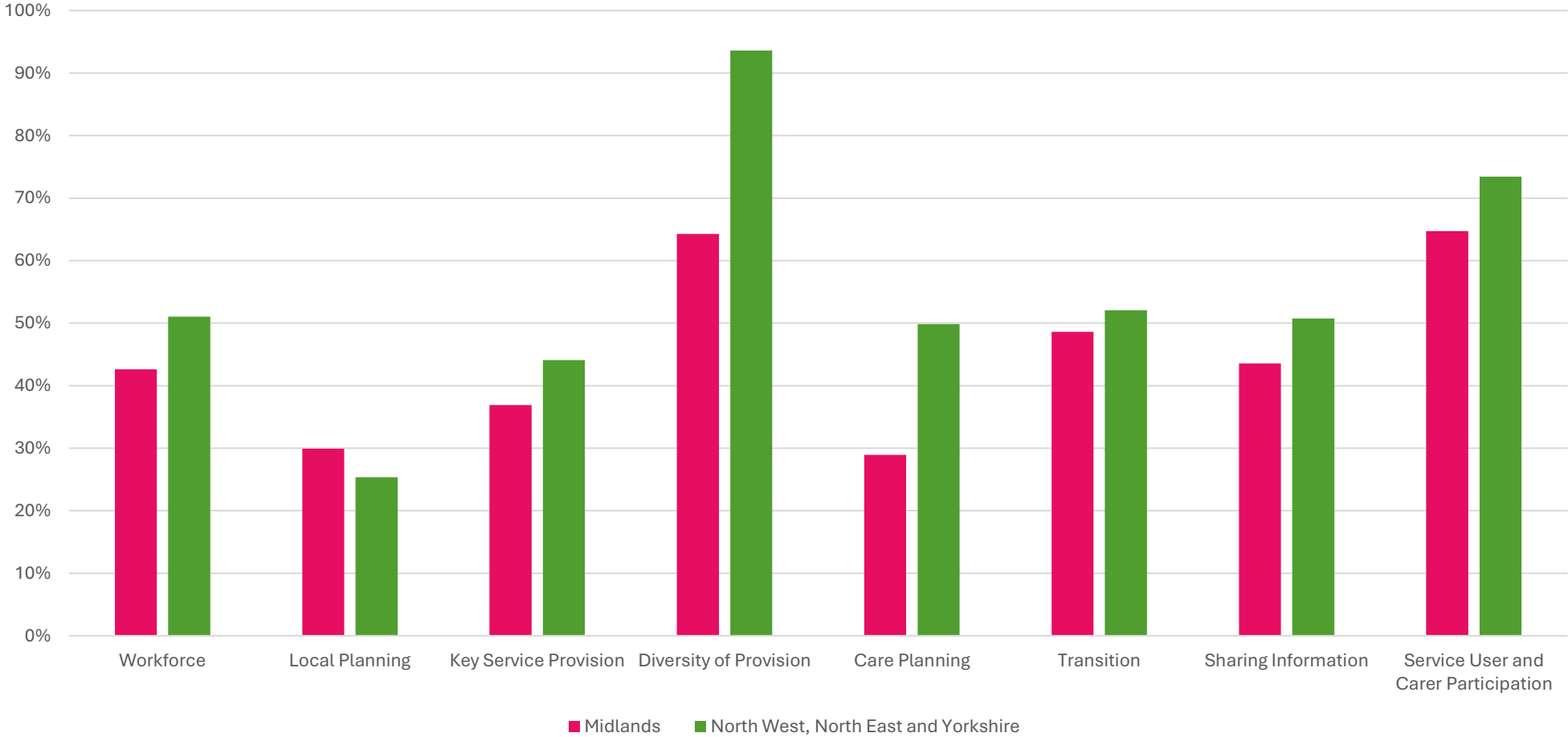
Overall results- by domain



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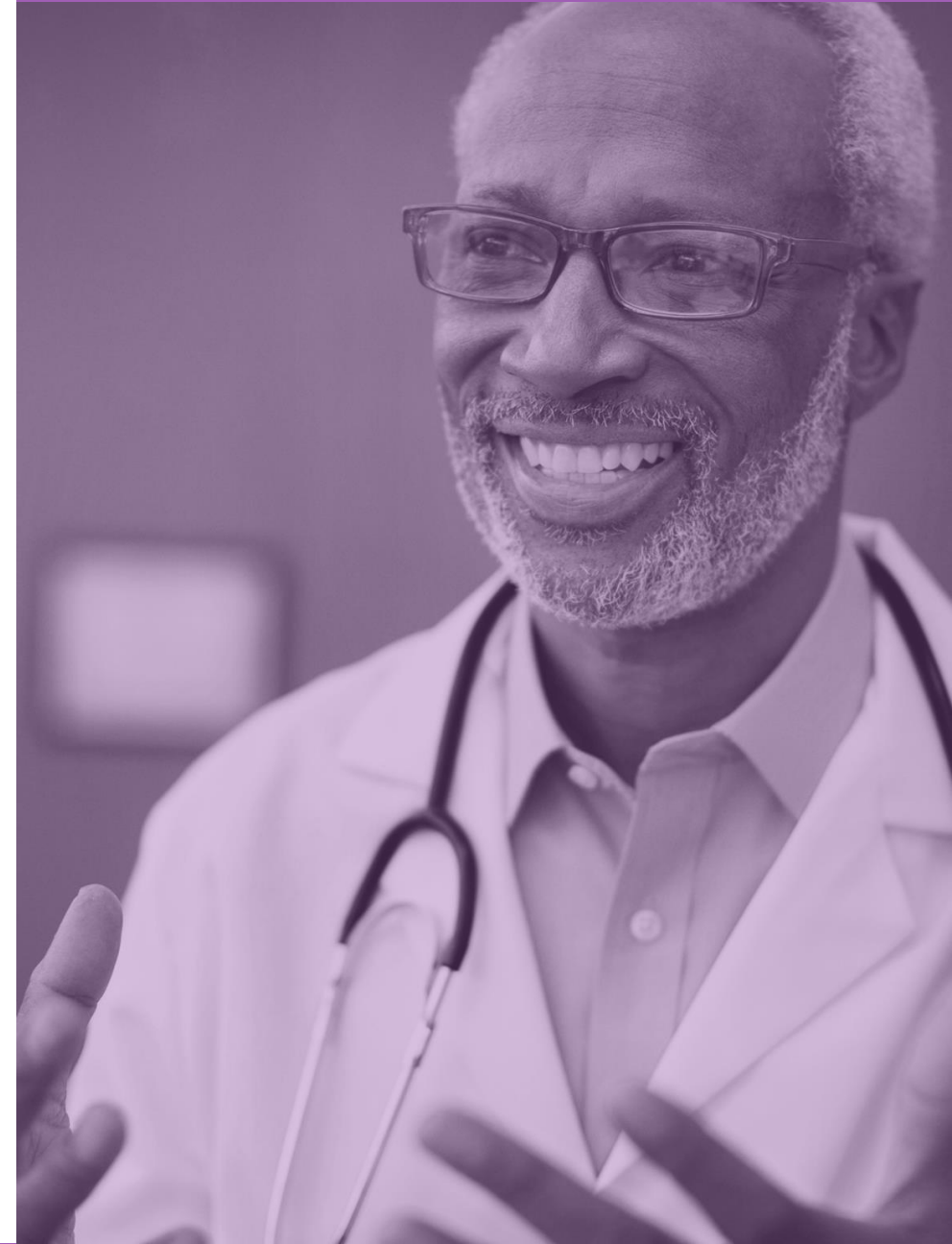


Overall results- by domain



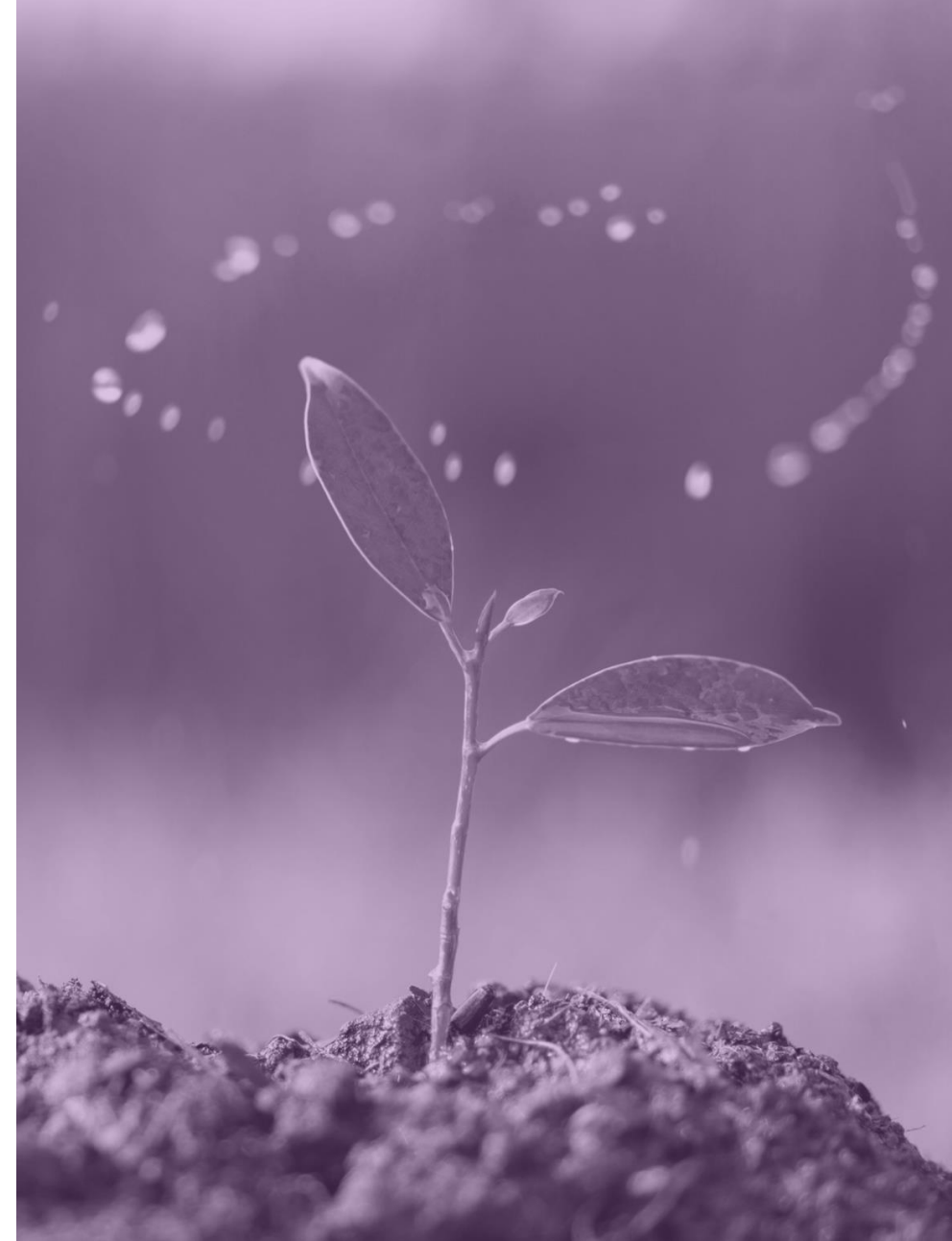
Widespread good practice

- Access to professionals and investigations
- Collection of ethnicity data
- Guidance on managing emergencies
- Providing feedback and receiving a response
- Assessments of carers' needs



Opportunities for growth

- Recruitment and retention
- Commissioning agreements
- Consistency of care across areas
- Shared care agreements
- Joint care plans
- Information sharing



What can you do?

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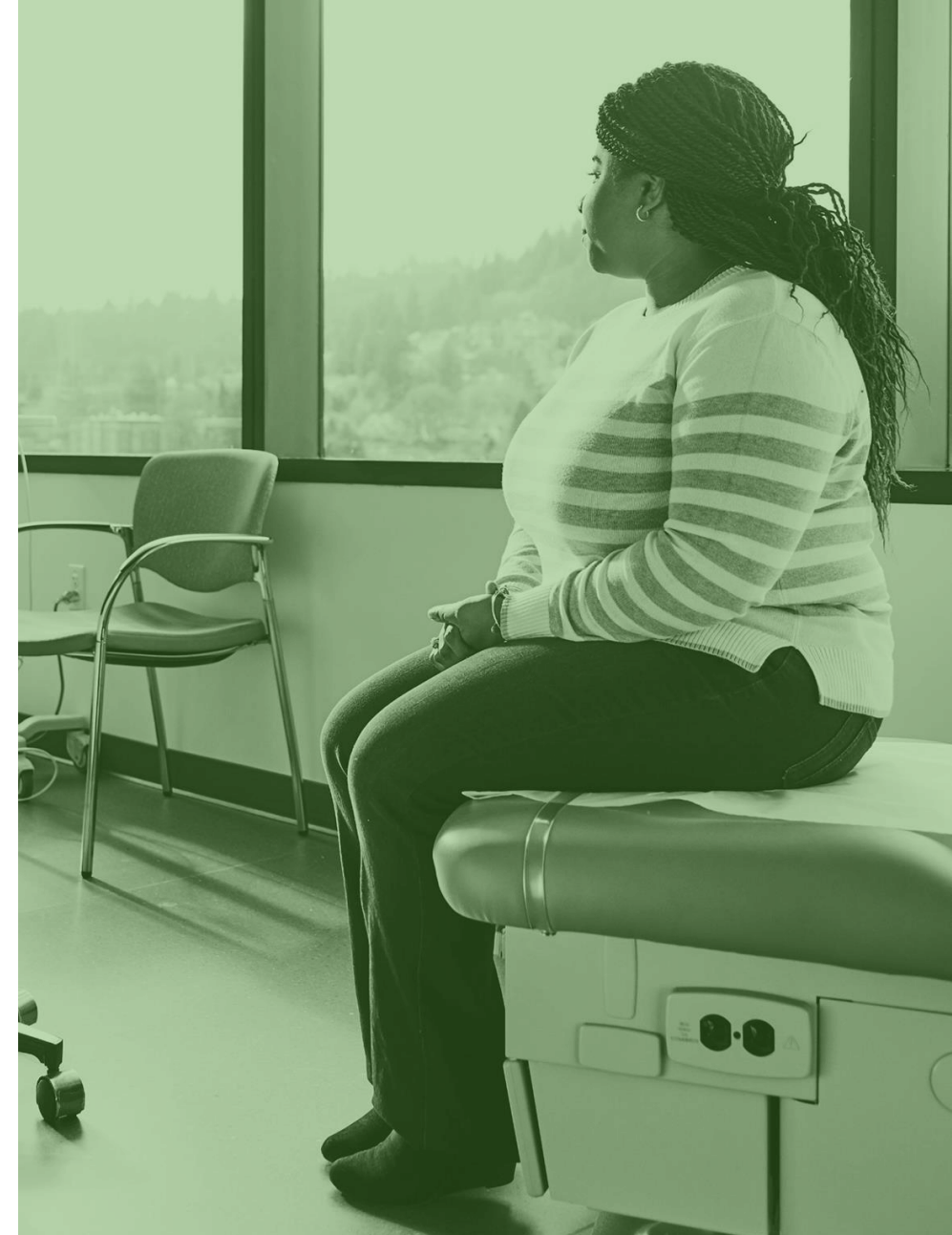
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Find out about your patients

- How many have epilepsy
- How does that impact them
- What barriers do they face
- What help would they like
- Care plans

Resources:

- Be Epilepsy Aware epilepsy.org.uk/BeEpilepsyAware
- Easy read booklets



Speak to your colleagues

- Which team is responsible for which aspects of care?
- Commissioning and provision arrangements
- The role of primary care
- Joint care plans
- Information sharing



Complete the toolkit!

Epilepsy.org.uk/StepTogether
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TShillito@epilepsy.org.uk



Thank you

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TShillito@epilepsy.org.uk



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