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Piloting Disability Disaggregation in Routine Data Collection

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A pilot in eye health

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- NGO founded in 1950

- Vision: a world where no one is blind from avoidable causes and where visually impaired people participate equally in society

- Annual income of ~£50 million p.a. (£200 million including in-kind drug donations)

- Employs >350 staff in > 30 countries

Disability Disaggregation pilot project

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The objectives of this project are to:

- Understand whether people with disabilities are accessing our services
- Build the evidence base to inform our own work, share with others and demonstrate the clear case for collecting disability data
- Ultimately make Sightsavers projects more inclusive of people with disabilities.

The two pilots are:
- Eye Health Project in Bhopal, India
- Neglected Tropical Disease (NTD) Project in Tanzania

Data Collection

- Data on disability integrated in to routine data collection

- Using the WG short set of questions

- Integrated as a demographic variable in existing data collection tools

- As this is a pilot we monitored:
  - Experiences of people involved in the project
  - Quality of the data collected

- Evaluation questions: How can data disaggregated by disability be collected on a **project level** in a **resource efficient way** that is **useful to policy and decision makers**.

Process findings and challenges from Tanzania and India

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Context: No single approach to data collection

Planning & flexibility: Data systems can be resistant to change

Ownership: Data collectors (& others) need to understand why data on disability is important

Expectations: Patients need to understand why we are collecting this data

Capacity: Analysing the data is necessary to initiate change

But … the process of engaging in the data collection has in itself a transformative effect.

Initial data from Bhopal, India

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On the data: A basic analysis of the data collected on over 16,000 patients in India during the first 10 months of the pilot shows that:

1. Prevalence of disability varies greatly depending on the cut-off used.

2. Reporting disability is linked to the location of services.

3. Prevalence of disability varies by sex depending on the definition of disability used.
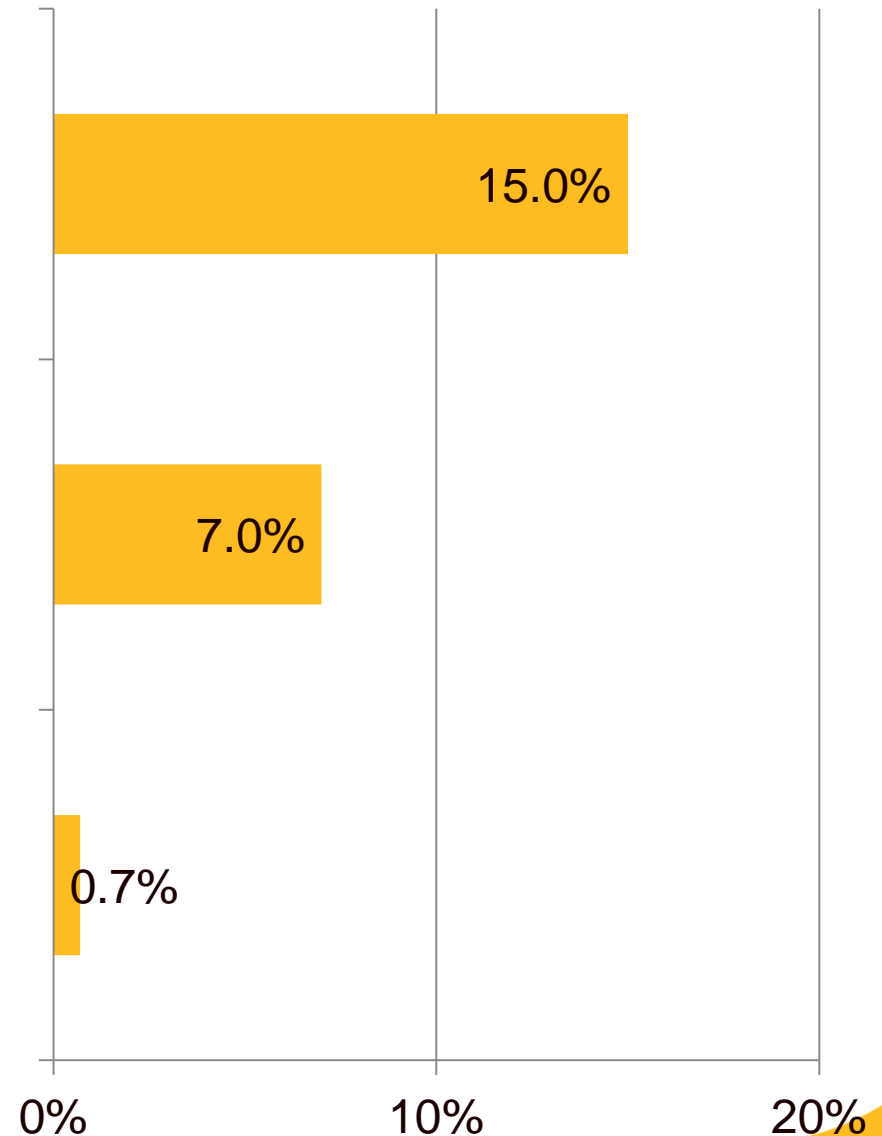
Initial data from Bhopal, India

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What proportion of our clients have a disability?

15% of project clients report **severe or completely limiting difficulties** in at least one domain.

7% when we exclude the sight domain.

0.7% when we ask them directly if they are disabled (as in the national census).

15.0%

7.0%

0.7%

0%   10%   20%

preliminary results subject to further data and analysis

Initial data from Bhopal, India

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Prevalence among clients according to service location:

Clients are **6 times more likely** to report a disability at the primary centre than the secondary centre

This rises to over **19 times** when excluding the sight domain

Males are **twice as likely** to go to the tertiary centre than females.

Females are more likely to report functional difficulties

Males are more likely to respond positively to direct questioning.

preliminary results subject to further data and analysis

WG Questions - lessons and challenges from Tanzania and India

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Translate, translate, translate.
- Qs 1 and 2 proved problematic in Hindi and were over complicated.
- Several iterations of testing has improved the speed and ease of asking

Analysis can be tricky without statistical expertise
- Technical skills mean a delay in programme staff accessing data
- Develop a user friendly software package for auto-analyses

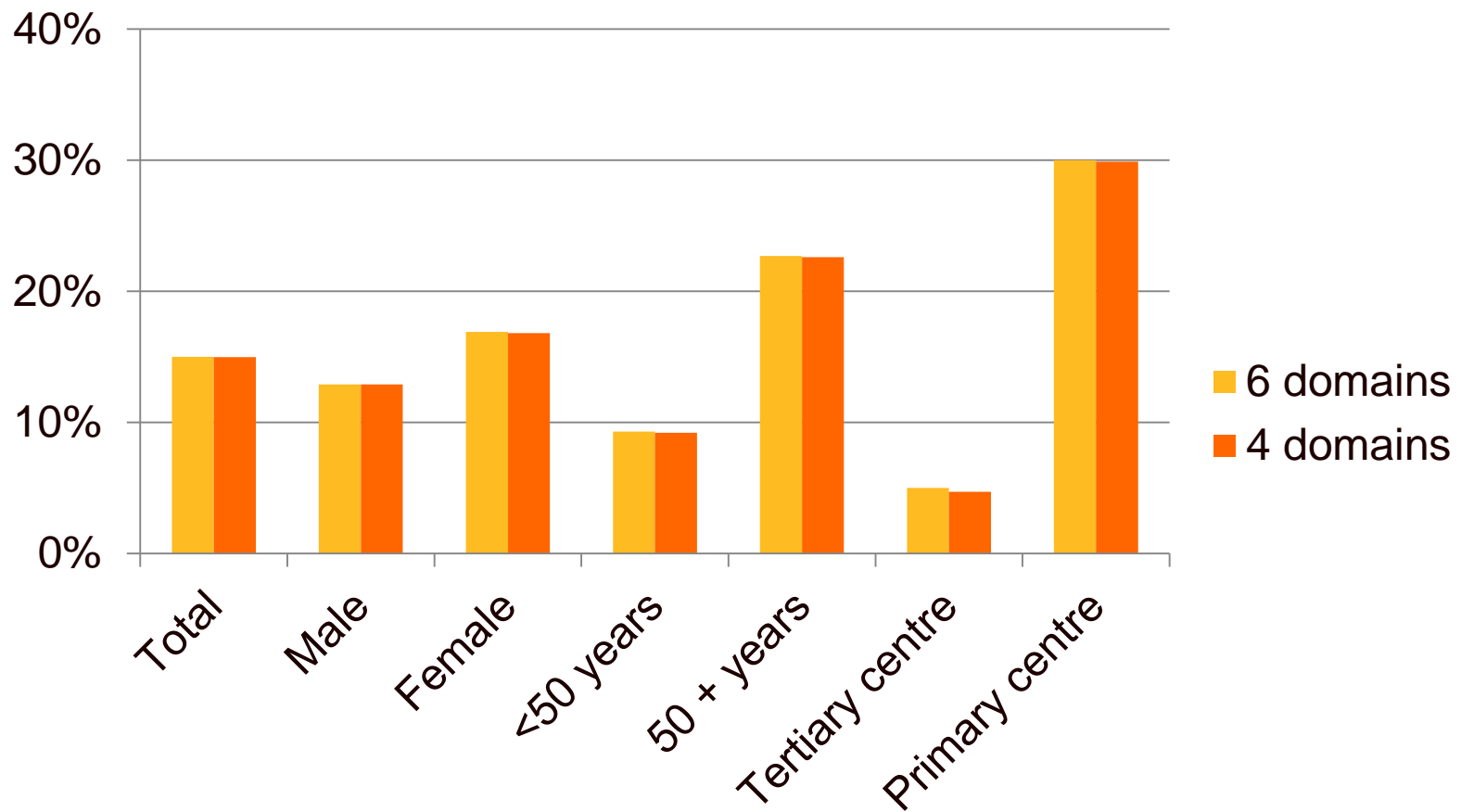# WG questions – lessons and challenges from Tanzania and India

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Questions 5 and 6 (domains: self-care and communicating) cause issues:

- Clients with no difficulties bored by this point
- Some report finding the questions offensive
- Staff feel clients answer 'No difficulty' repetitively just to finish quickly

Conducted a sensitivity analysis to understand how excluding these questions would change our results

WG questions – lessons and challenges from Tanzania and India

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How does prevalence change when we remove the two domains?

What next?

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India:
- Created awareness and demand which did not exist
- Partner organisations changed community communication practise and referrals
- Confirmed plans for Sightsavers to pilot inclusive approaches to eye health to improve accessibility to services we support in 2016.

Tanzania: end of project evaluation November 2015

Ghana: new pilot, data collection taking place in 2016
- Mass Drug Administration in general population for neglected tropical diseases.
- Community data collectors

Lessons for replication?

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- Disaggregation requires commitment to include people with disabilities in services

- It is only the beginning of a fundamental shift to inclusive services

- The data collection process itself can awaken the need for inclusive services and stimulate the demand to provide them.

- Before investing in data systems, it is imperative to ensure that the data can and will be used by people with power to implement change.