Are we a resource-poor setting too? Challenges in improving the coverage and quality of continuing care for people with dementia in the UK

Martin Prince

No conflicts of interest

Centre for Global Mental Health
Health Service and Population Research Department
King's College London
1066drg@iop.kcl.ac.uk

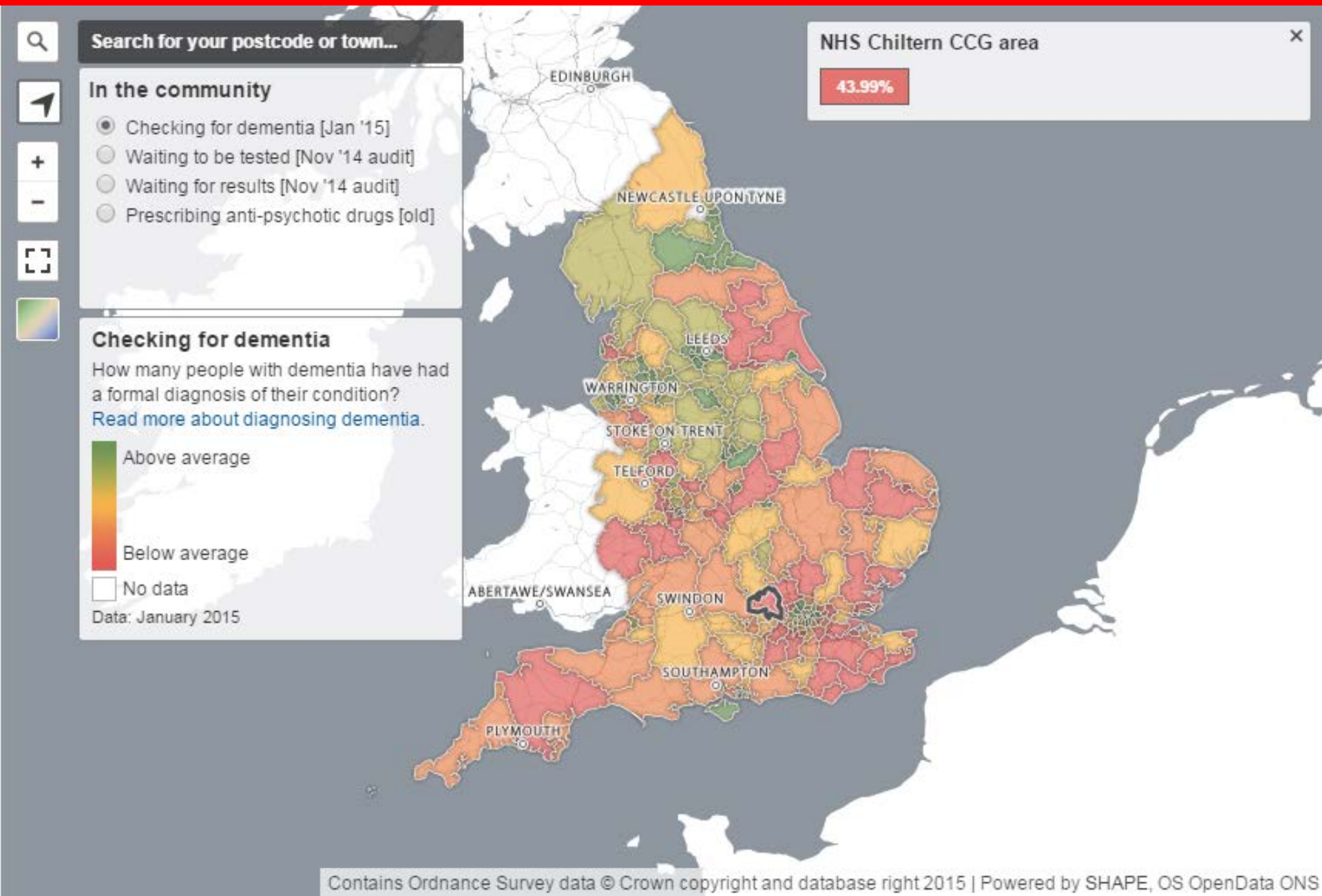
Coverage

- In high income countries
  - Diagnosis is late, if ever
  - 40-60% have never received a diagnosis (World Alzheimer Report 2011)
- In low and middle income countries
  - People with dementia are less likely than others to use health services (10/66, Albanese et al 2011)
  - Clinic based services, no continuing care, out of pocket payments
  - Treatment gap exceeds 90%, e.g. Brazil (Nakamura, 2015), India (Dias et al 2009) and Thailand (Jitapankul et al 2010)

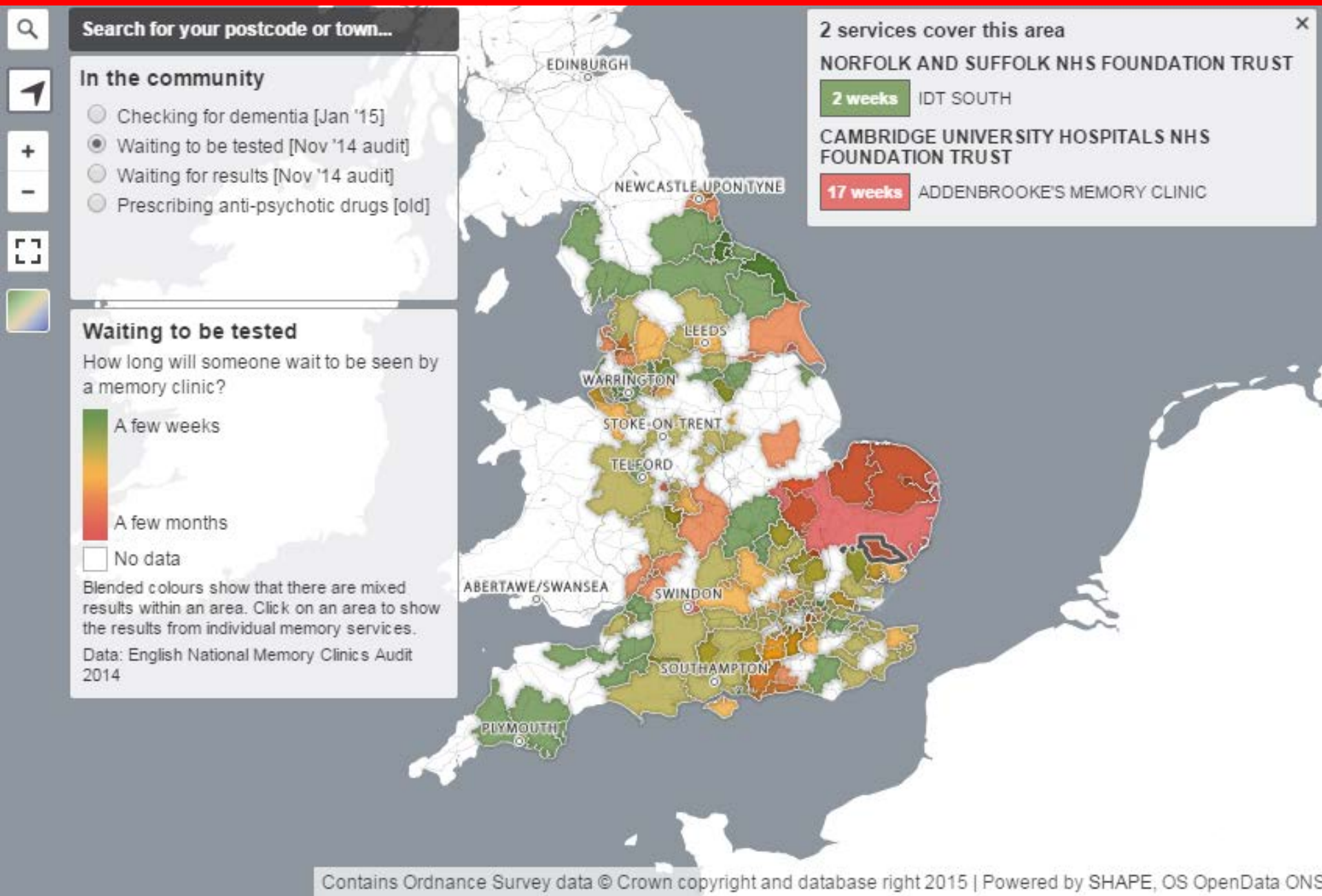
Challenges in LMIC

- Social care
  - sustainability of traditional family care system
  - no structured services to support (or supplement/ substitute) informal care
  - no policies to incentivise informal care
- Health care
  - few specialists
  - primary/ community care not engaged
  - no outreach
  - fragmentation of services
  - Financing (out of pocket expenses)
- and in HIC?.....

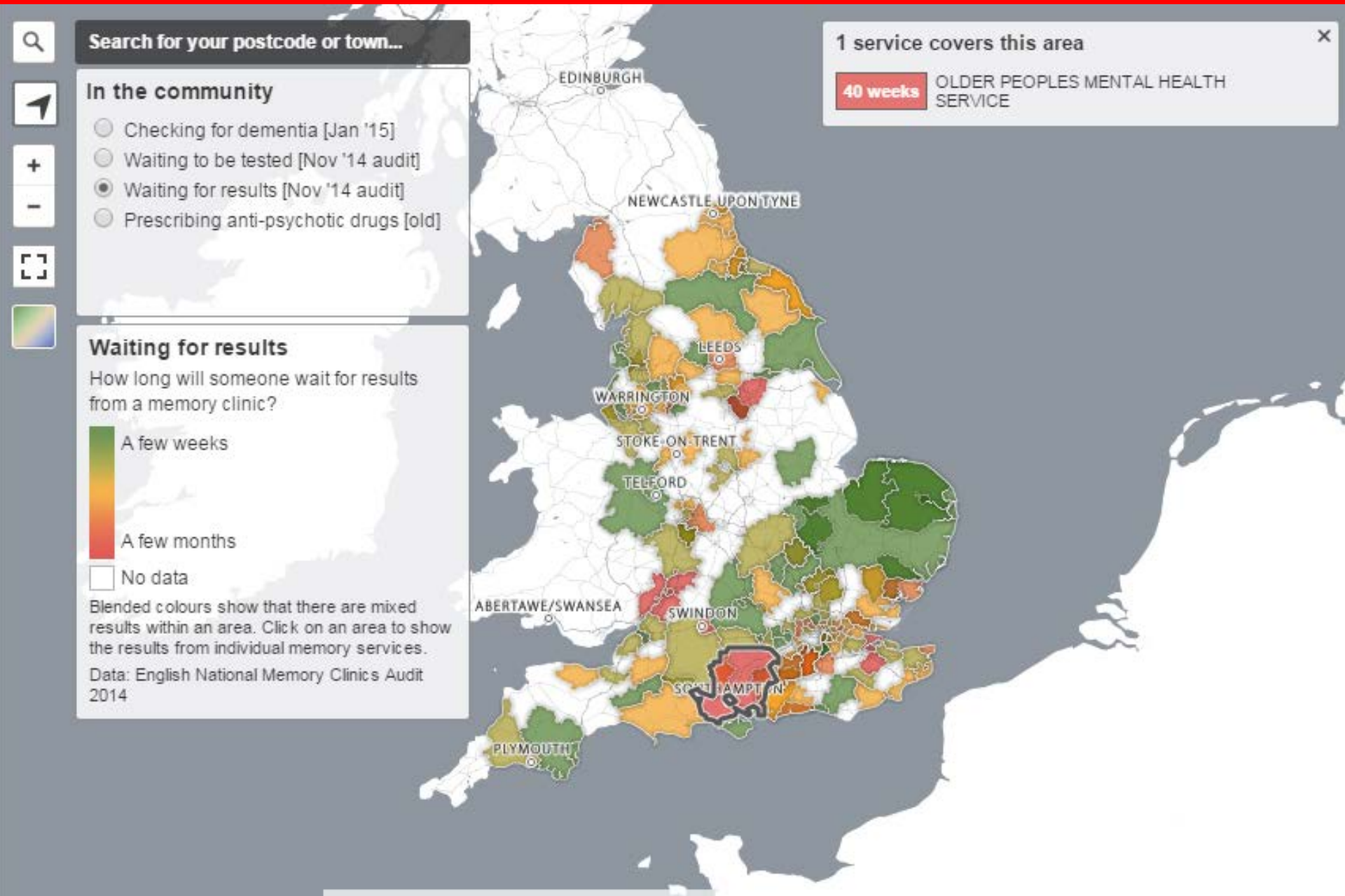
Diagnostic coverage (43-75%)



Memory clinic wait lists (2 wks- 4 mths)



Assessment results (4-40 weeks)

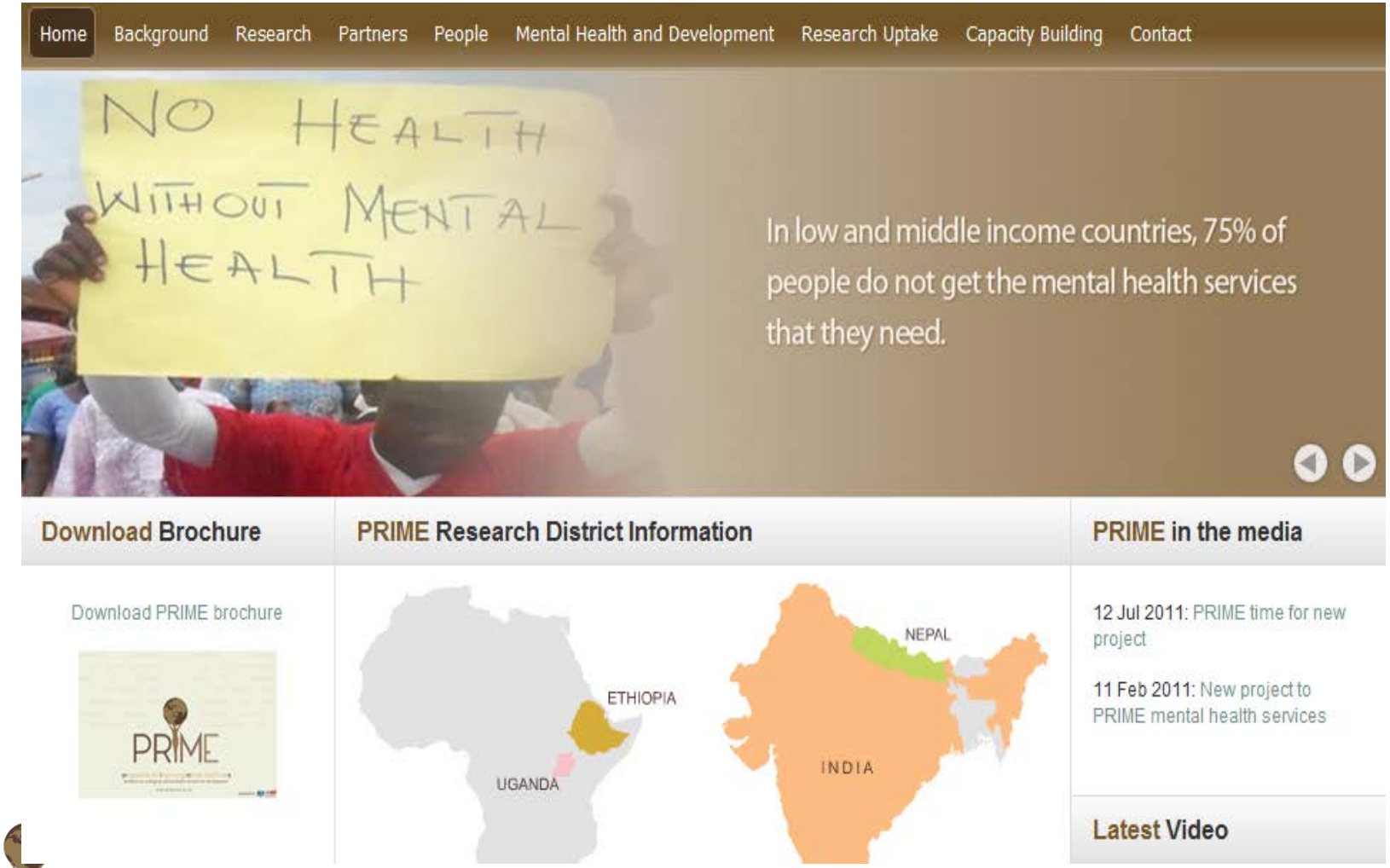


Principles (public health model)

- Integration
  - into primary care roles and functions
  - between health and social care
- Task-shifting/ task-sharing
  - most services provided at primary care level by non-specialists
  - trained and supported by specialist services
- Reduce barriers to access
  - outreach (essential)
  - financing mechanisms
- Attention to structural/ societal issues
  - awareness
  - long-term care
  - social protection/ equity

Lessons from Global Mental Health

PRIME Study: www.prime.uct.ac.za



PRIME

programme for improving mental health care

How can we make chronic disease care work?

- “effective chronic illness management requires comprehensive system changes that entail more than simply adding new features to an unchanged system focused on acute care”
- “the introduction of guidelines, and/ or disease registries have not led to significant improvements in processes or outcomes, which typically only arise from more fundamental changes to the design of practice”

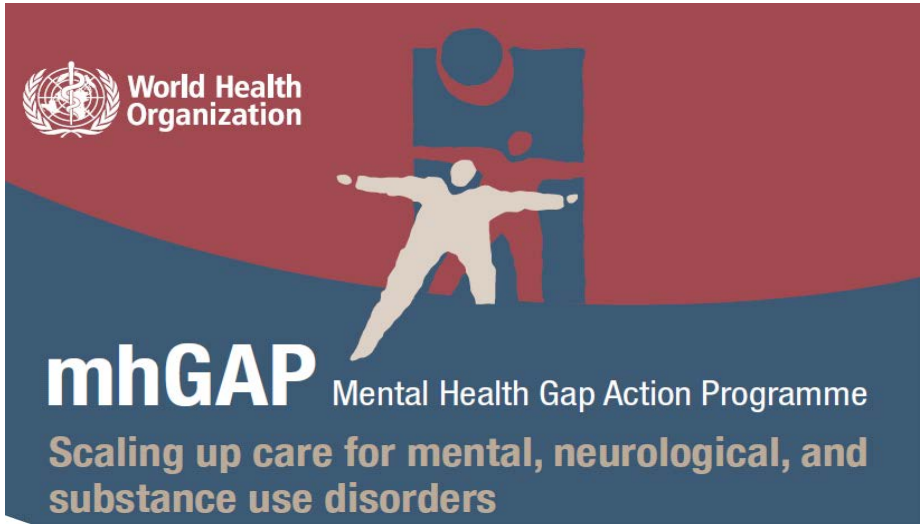
Wagner et al. Improving chronic illness care: translating evidence into action. Health Aff (Millwood) 2001

DFID PRIME – working at three levels

- **Health care organisation (AHU)**
  - Governance, financing, human resources, information systems
  - Estimate the health system requirements and costs for local level scale up
- **Health care facility**
  - Detection and treatment of priority mental disorders, using evidence-based treatments and non-specialist health workers
  - Collaborative stepped care model
- **Community**
  - Awareness raising, stigma reduction
  - Early identification and referral
  - Continuing care/ rehabilitation
  - Health extension workers, and others outside of formal health sector

Packages of care for dementia

* Evidence to support these components from LMIC



- * Casefinding
- * Brief diagnostic screening
- Making the diagnosis well – information and support
- Attention to physical comorbidity (and nutrition)
- * Carer interventions (carer strain)
- Timely assessment, treatment and support across the course of the condition

Prince et al, PLOS Medicine 2010

A diagnosis ‘well-made’ – can we do this in primary care?

- preparation
- integrating family members
- exploring the patient's perspective
- disclosing the diagnosis
- responding to patient reactions
- focusing on quality of life and well-being;
- planning for the future;
- communicating effectively

Lecoutourier, 2008

Physical health problems in dementia
10/66 prevalence studies

	No dementia	Dementia		
		Very mild	Mild	Moderate or severe
Pain	36%	35%	30%	18%
Incontinence	1%	8%	17%	54%
Vision	34%	42%	45%	40%
Hearing	16%	27%	28%	30%
Mobility	12%	28%	37%	68%
Undernourishment	3%	9%	9%	18%

Prince et al, IJGP 2010

Integrated Care for Older People (WHO I-COPE)

VERTICAL
(HEALTH CONDITIONS)

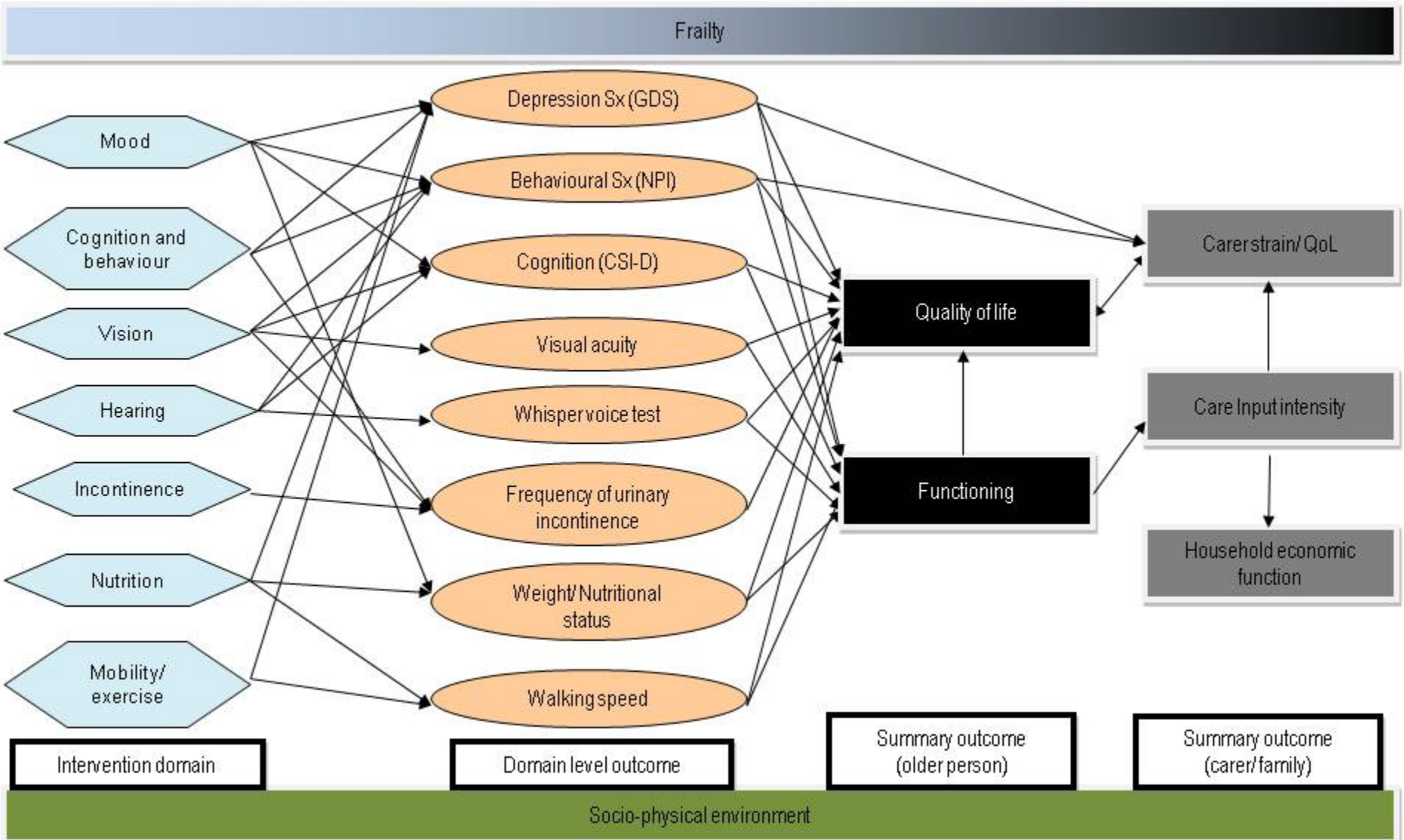
- Dementia
- Stroke
- Parkinson's disease
- CHD
- COPD
- Depression
- Arthritis
- Anaemia

HORIZONTAL
(IMPAIRMENTS)

- Confusion and behaviour disturbance
- Mood
- Immobility/ Falls
- Incontinence
- Undernutrition/ hydration
- Sensory impairment
- Carer knowledge and strain

HOME-BASED/ TASK-SHARING/ OUTREACH/ LOW COST

Theoretical framework (synergistic effects) WHO ICOPE



The Goa COPE study

- Formative qualitative research
- Case-finding by health workers
- Validation of the COPE assessment tool
- Integrating packages of care

AT et al. BMC Geriatrics (2015) 15:123
DOI 10.1186/s12877-015-0121-1

BMC Geriatrics

RESEARCH ARTICLE Open Access

Identifying common impairments in frail and dependent older people: validation of the COPE assessment for non-specialised health workers in low resource primary health care settings

Jotheeswaran AT[1,7*], Amit Dias[4,5], Ian Philp[3], John Beard[7], Vikram Patel[2,5,6] and Martin Prince[7]

Summary of formative qualitative research

- Unmet needs of frail and dependent older people were generally acknowledged, and seen to be a problem
- CHWs were knowledgeable about impairments and their impact on older people and their families
- Lack of access to a facility-based service seen as major barrier
- Limitations/ obstacles to outreach service
  - Defined roles and responsibilities of outreach CHWs
  - Knowledge and skills
  - Time and manpower
  - Perceived lack of home-based interventions
  - Referral pathways

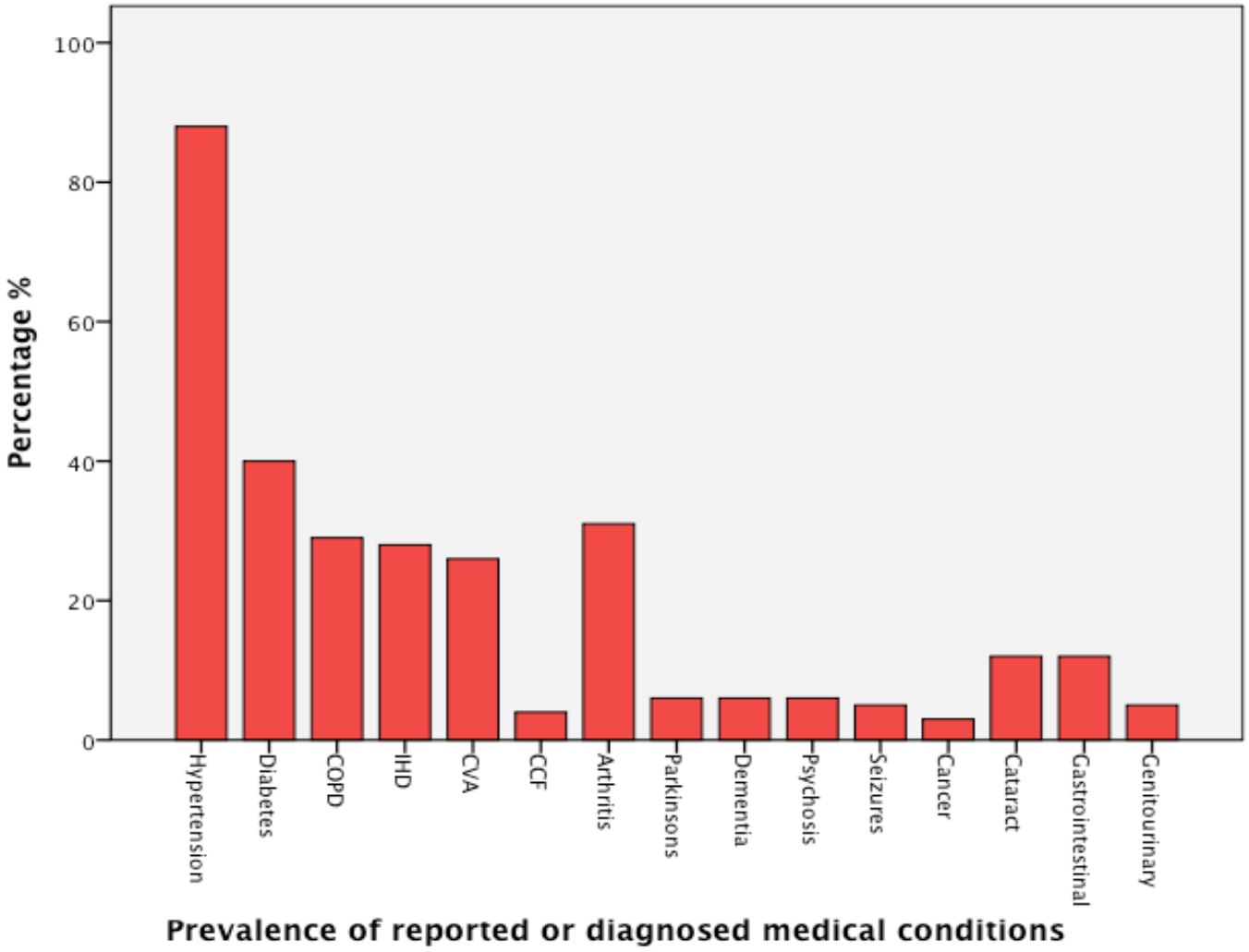
COPE case-finding study

- 10 CHWs working in the Goa public health system
- Trained for three hours in the monthly meeting
  - Frailty
  - Dependence (needs for care)
  - Causes/ consequences
  - Vignettes and case discussion
- Each asked to identify and assess 15 frail or dependent older people from their community (total n=150)
- Cases then assessed by local primary care physician with an interest in elder care

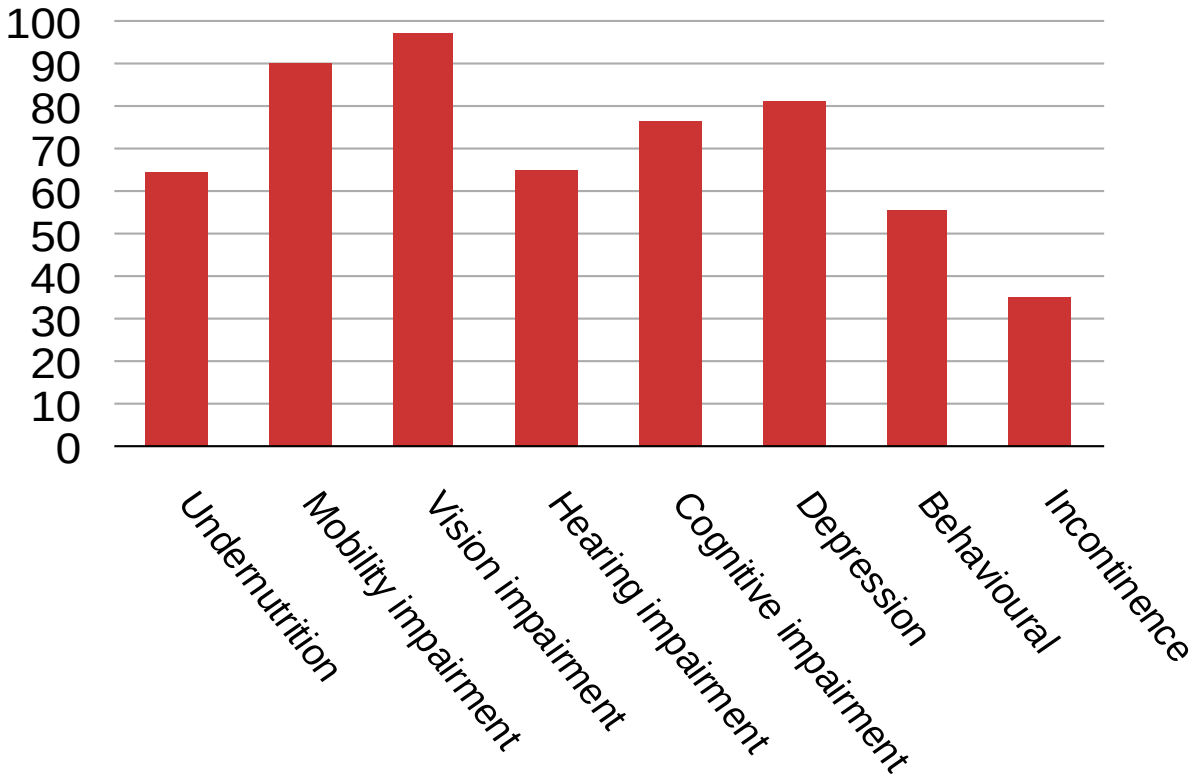
Case-finding study

- Clinicians confirmed a high prevalence of relevant indicators, among the older people selected by the CHWs
  - 59% multimorbidity
  - 84% multiple impairments
  - 42% polypharmacy (taking three or more medications)
  - 73% risk of falls
  - 79% reported needing some help to access health care facilities and 17% could not access these services

Prevalence of disorders (clinician)



Prevalence of impairments (clinician)



The COPE assessment tool

Impairment	Assessment
Nutrition	MNA – MiniNutritional Assessment
Mobility	Walking speed, chair stand
Vision	Snellen chart – tumbling E's
Hearing	Whisper voice test
Continence	Self-report
Cognition	Brief CSI-D – Community Screening Test for Dementia
Mood	GDS-8 – Geriatric Depression Scale
Behaviour	NPI-Q – Neuropsychiatric Inventory

Agreement between CHW and clinician

Impairment	CHW prev%	Clinician prev%	PPV%	Kappa
Nutrition	54	65	78	0.28
Mobility	82	91	93	0.14
Vision	46	99	99	-0.02
Hearing	68	66	75	0.33
Continence	22	35	74	0.41
Cognition	38	78	88	0.12
Mood	60	82	89	0.20
Behaviour	48	56	72	0.31

Nutritional intervention – Phase II trial (feasibility, acceptability, efficacy)

Assessment and management of undernutrition in frail older people

Does the older person have undernutrition?

Look for:
Physical appearance e.g. thin or very thin
Recent unplanned weight loss
Loose fitting clothing/jewellery,
Changes in appetite

Ask for:
- Ability to eat and drink (need for assistance with feeding)
- Swallowing difficulties, vomiting, chronic diarrhea, abdominal pain or swelling

Assess:
- Administer Mini Nutrition Assessment

Assess the current dietary pattern?

Ask for frequency of consumption and no of serving:
- Cereals (ragi, rice, chapatti)
- Pulses and legumes (moong, dhal, chana, alsande, peas, chavli)
- Milk and milk products (curd, buttermilk, paneer, cheese, ice cream)
- Vegetables (leafy: methi, spinach, amaranth etc and beans, cauliflower, potato, brinjal, etc)
- Raw vegetable (tomatos,cucumber,cabbage,carrot etc)
- Fruits (apple,orange,banana etc)
- Fried foods (samosa,mirchi,bhaji,kappa etc)
- Deserts and sweet snacks (biscuits, cake, pastry,mithai,halwa etc)
- Aerated drink (coke,pepsi etc)
- Salty snacks (chips, chiwda, sev etc)

YES

If MNA score is 7 or less

- Provide dietary advice as mentioned in the management section 2.1
- Prescribe oral nutritional supplement as recommended in section 2.2
- **DO NOT** recommend oral nutritional supplement if the person has following conditions (Swallowing difficulties, vomiting, chronic diarrhea, abdominal pain or swelling)

NO

If MNA score is more than 7 and less than 11

- If dietary intake is inadequate provide dietary advice as recommended in section 2.1
- re assess the older person after three months

WHO I-COPE – a public health approach

- Improving coverage
- Affordable, accessible
- Scalable
- Community level/ home-based
- Using existing non-specialist resources
- Using existing outreach capacity
- Successful implementation would require
  - Role redefinition of CHWs
  - Increased capacity (more CHWs?)
  - Training and support
  - Further work on home-based intervention, and referral pathways

What next

- **A WHO Dementia Action Plan**
- **A WHO Observatory to monitor progress**
- **Implementation and evaluation of evidence-based, scaleable, packages of care in resource poor settings**

- **Are we ‘resource poor’ in HIC too?**
- **Models of care too reliant on specialist services?**
- **More of a role for primary care services?**
  - **Diagnosis**
  - **Post-diagnostic support**
  - **Continuing care**
  - **Integrated and holistic care (WHO I-COPE?)**
  - **Care coordination**