Cancer – as a long term condition

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5 November 2009

WE ARE MACMILLAN. CANCER SUPPORT

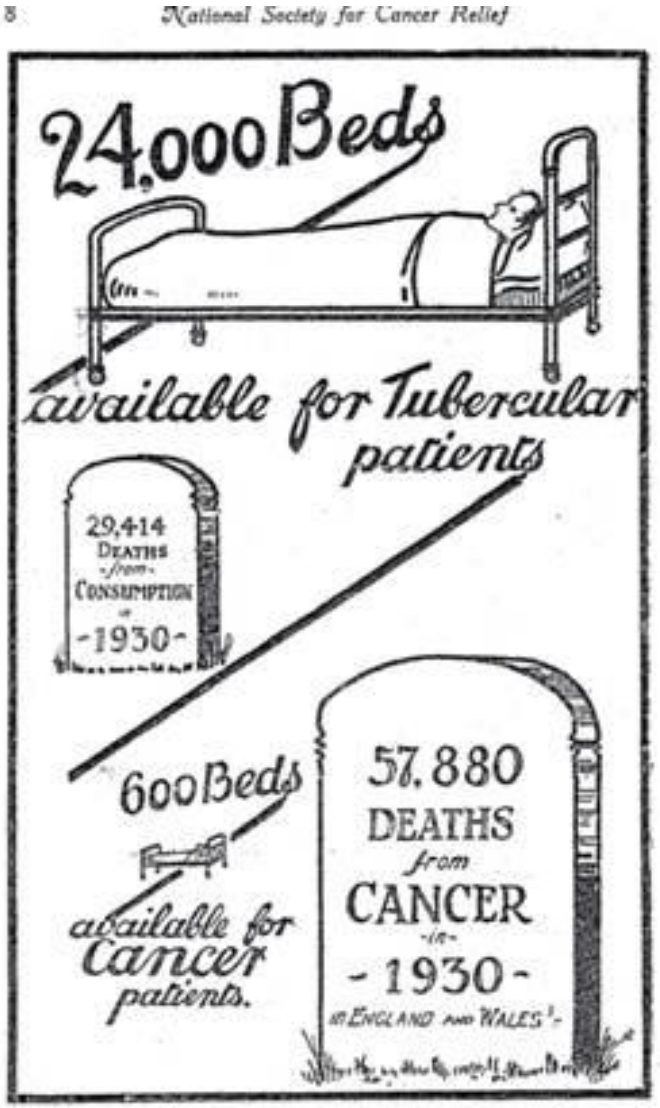
Cancer has come along way ???

No beds

Palliative Care

Macmillan Nurse

Living with Cancer



MACMILLAN'S AMBITION IS TO REACH AND IMPROVE THE LIVES OF EVERYONE LIVING WITH CANCER

2 MILLION

Who are the two million cancer survivors?

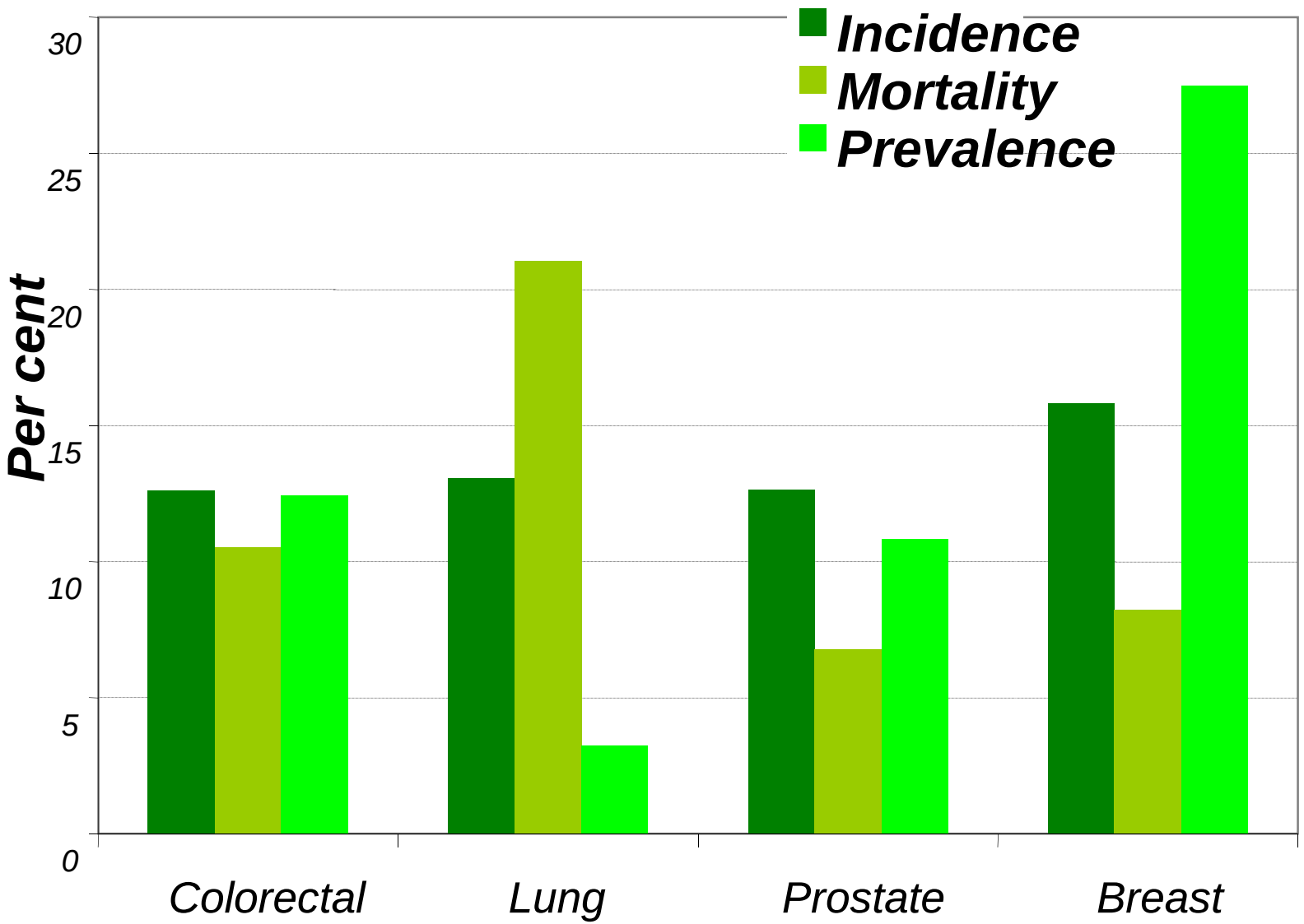
Sex	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60

Age	Cancer survivors	%
0-17	16,000	0.8
18-64	774,000	38.7
65+	1,210,000	60.5

What cancers are they living with?

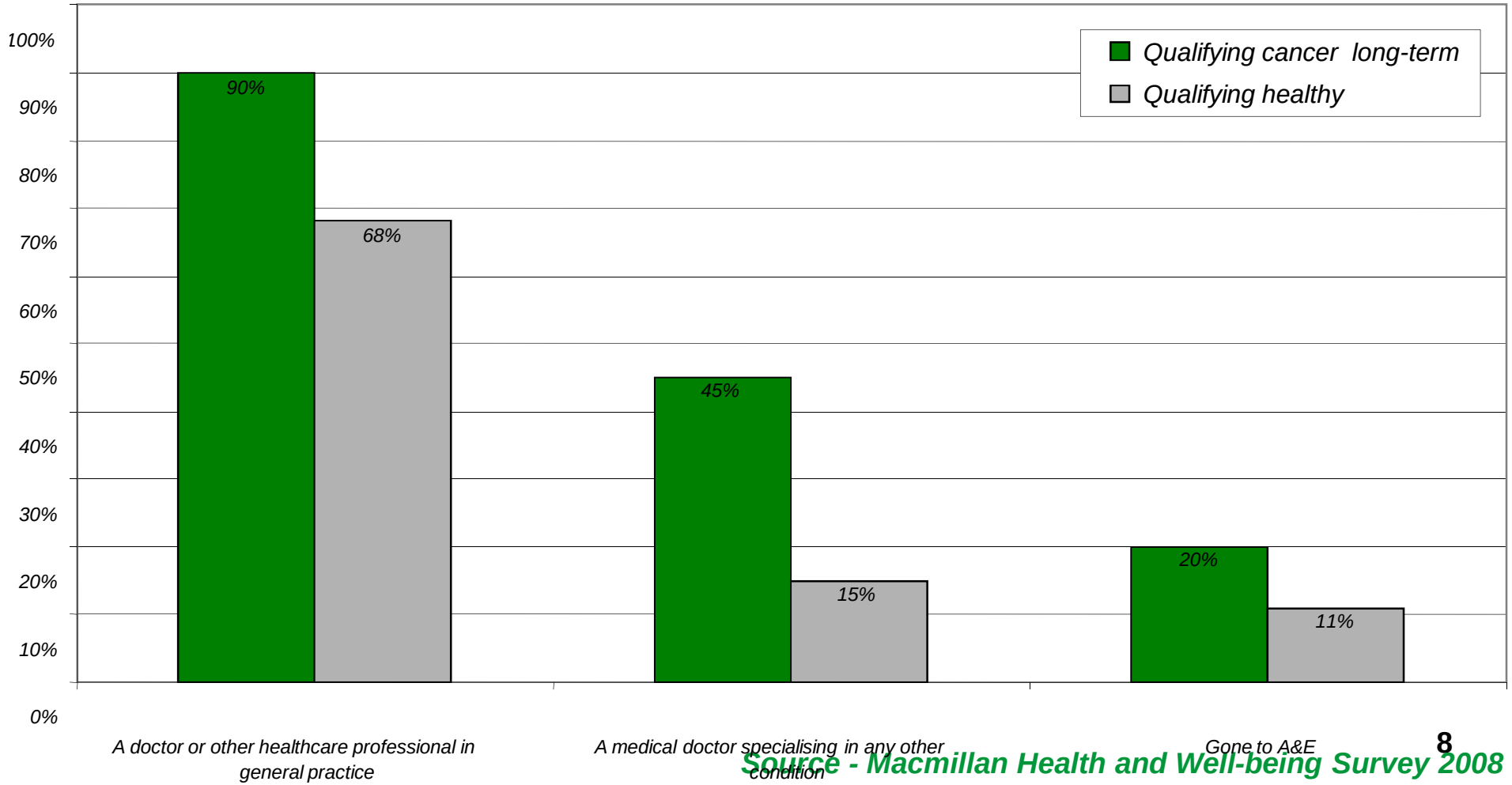
Cancer Site	Cancer survivors	%
Colorectal	250,000	12
Lung	65,000	3
Breast	550,000	28
Prostate	215,000	11
Other	920,000	46

Prevalence by site differs from incidence and mortality by site



Long-term cancer survivors use the NHS more than healthy people . . .

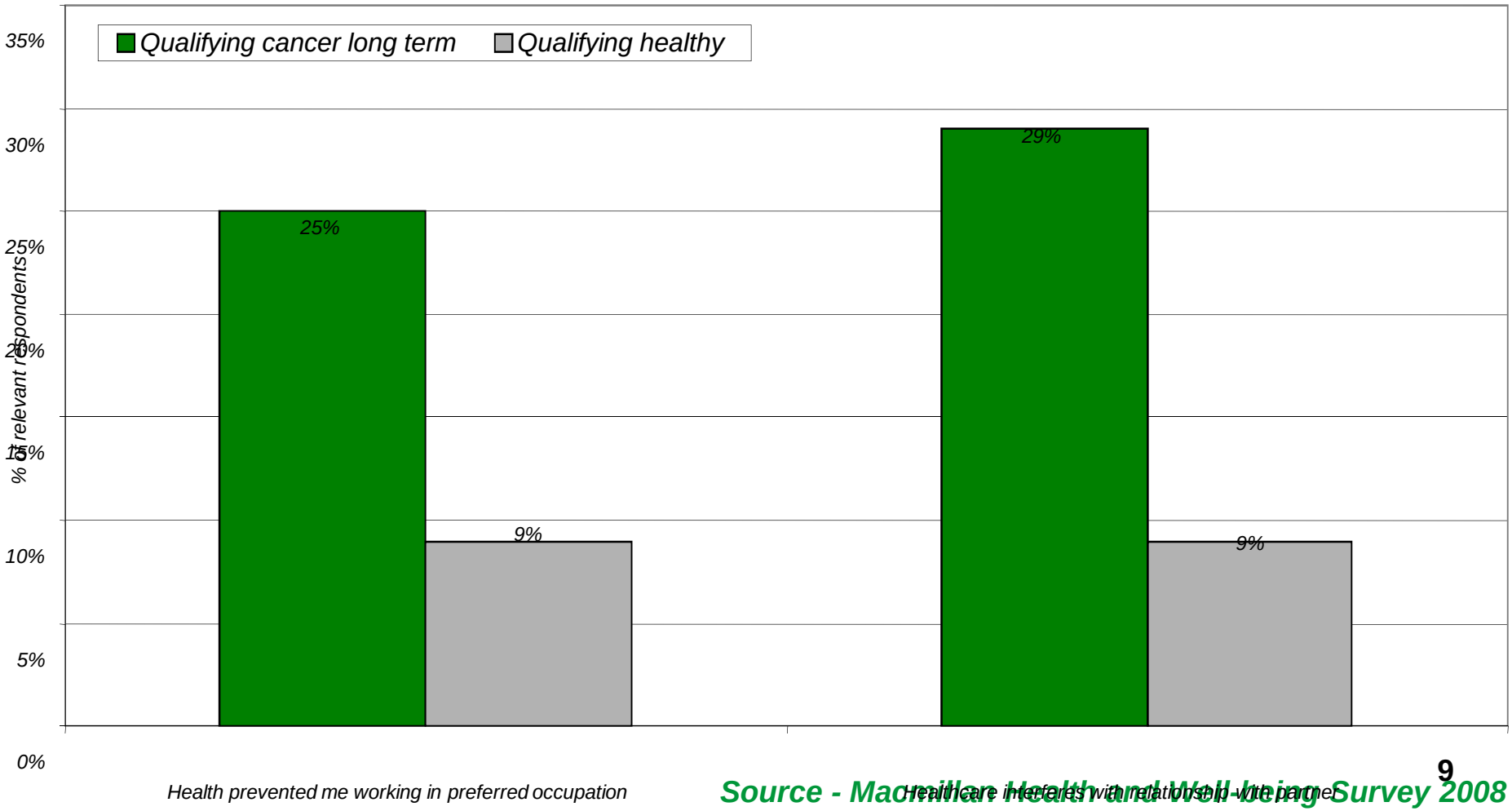
Which of these have you seen/talked to about your health / done in the last 12 months?



Source - Macmillan Health and Well-being Survey 2008

Cancer impacts both work and relationships . . .

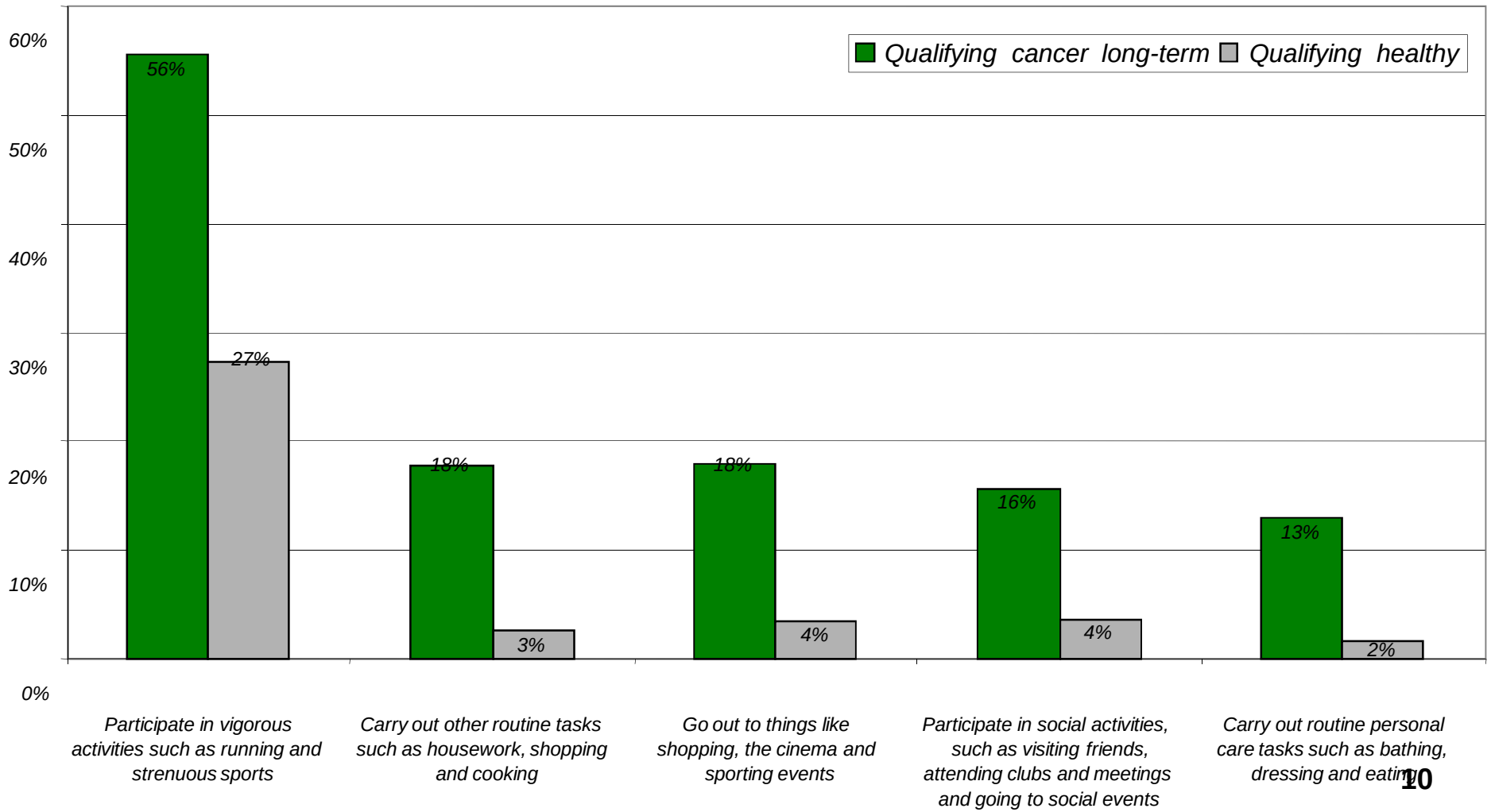
% who agree strongly or slightly with statements



Source - Macmillan Health and Well-being Survey 2008

Living life is tougher whether doing vigorous or mundane activities

% finding ... somewhat difficult/very difficult/cannot do at all



Source - Macmillan Health and Well-being Survey 2008

We have currently have seven workstreams with three more on the way

Assessment and care planning

Managing active/progressive disease

Late effects

Children and Young People

Work and finance

Self management

Research

Cross-cutting themes
(Information/workforce/ commissioning)

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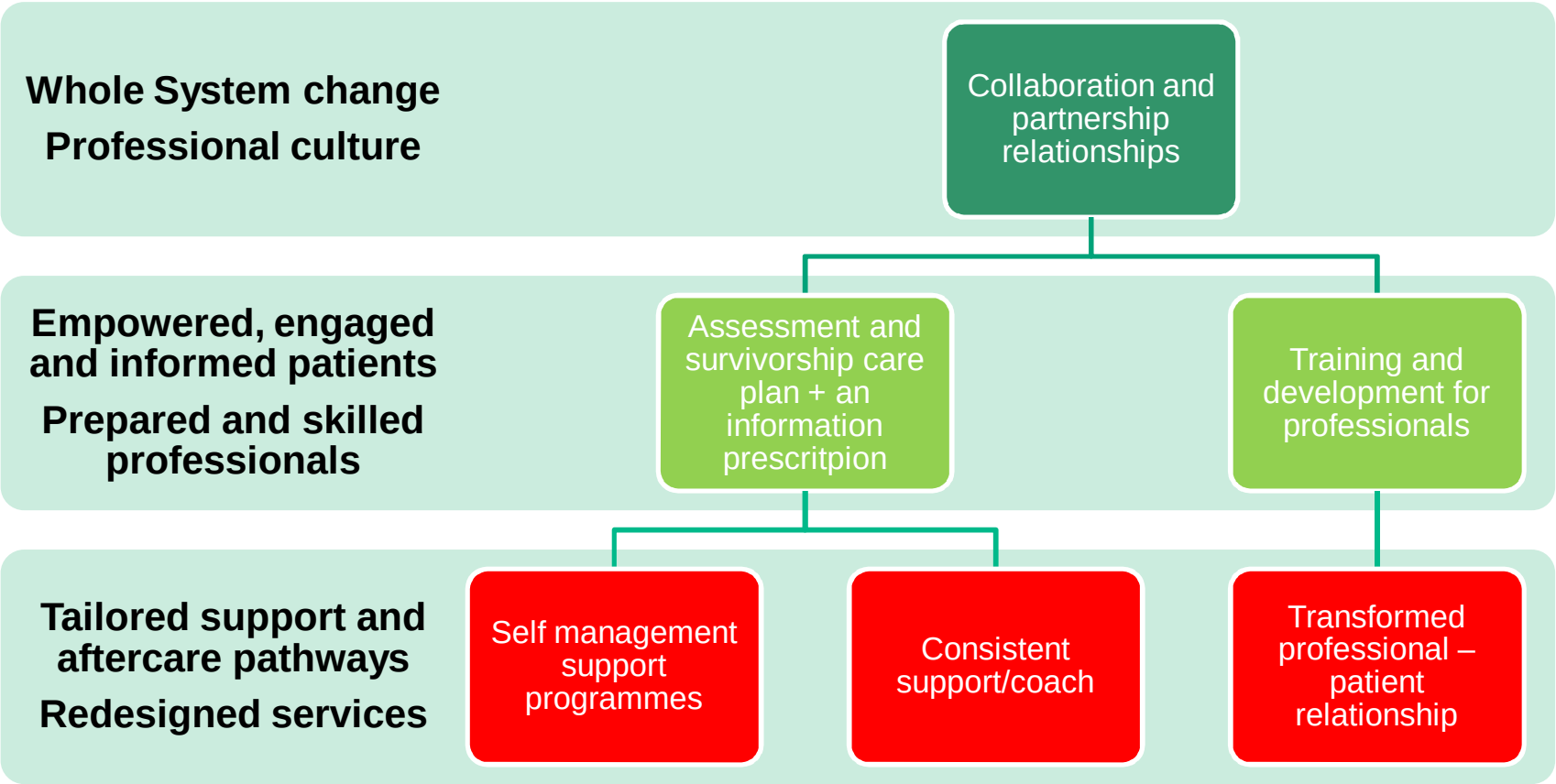
3.2%

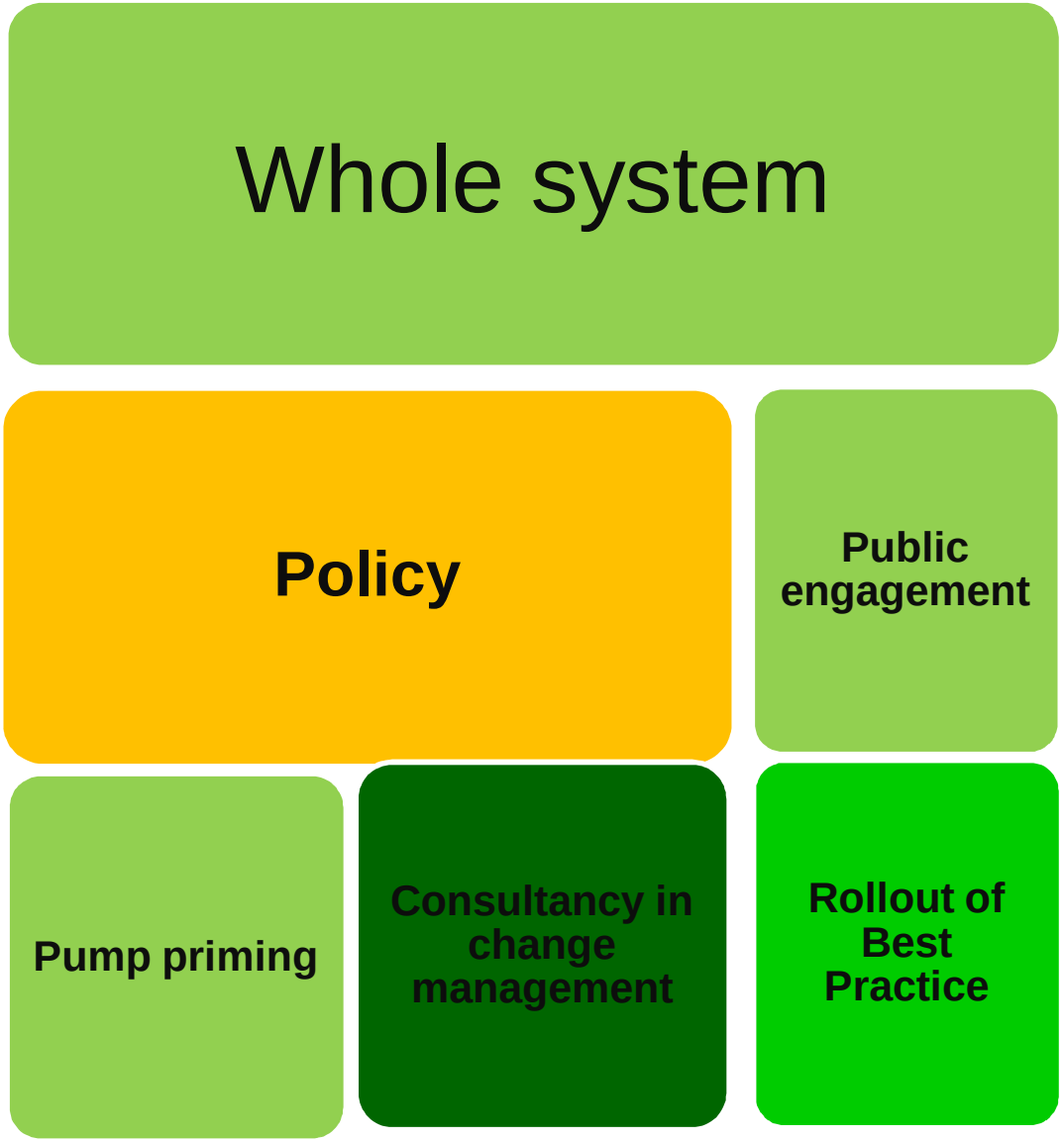
Why is this important. . .

- **Many of those not in active treatment will need emotional support**
- **Cancer survivors are hit hard financially**
- **They may not all have active disease but that does not mean they are well**
- **Those with active disease are living too**

Supported Self Management framework



Our model of innovation



- It takes time
- Investment
- Project management
- Organisational ownership and commitment
- Partnership working

People with cancer have told us what the issues are . . .

We must help people to access the support they need

Some aspect of the National Cancer Survivorship Initiative's work

Impact of cancer does not stop when treatment is over – first year is a difficult one

Impact on lifestyle factors

A chronic condition

Patients want coordinated health and social care

- Jan Bolton, Social Care Coordinator, Northampton General Hospital in the Centre for Oncology

2 MILLION

THANK YOU

Improving Services for People with Motor Neurone Disease

Michelle O'Brien
Senior Team Leader (London)

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MND

- Rapidly progressive degenerative disease
- Currently no cure. Average prognosis from diagnosis to death is 14 months
- Complex health and social care needs
- Prevalence of 7:100,000
- Requires a pre-emptive approach
- Care MUST be multidisciplinary and multi-agency
- Referrals, diagnostics, assessments – all have to be expedited for people with MND

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A future world free of MND…

- Funding and promoting research to find the causes of, diagnostics and effective treatment of MND
- Enable everyone with MND to receive the best care, achieve the highest quality of life possible, and die with dignity
- Support the families and carers of PwMND

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What the MND Association offers?

- MND Connect
- Information
- www.mndassociation.org
- Research opportunities
- Equipment loan and financial support

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Regional Care Development Advisors (RCDAs)

- have **detailed knowledge** of the care and management of MND
- **work closely with local statutory providers** across primary, secondary and tertiary care to ensure effective, joined-up services
- **offer support and advice to people with MND and their families**
- **act as educators, facilitators and catalysts for change**
- work closely with **branches and Association Visitors**

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Influencing standards of service

- **MND Care Centres** – The National, Kings, Barts and the London
- Working with MDTs to implement **Standards Of Care**
- **Influencing national policy**

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The London Project – why?

- Population of 7.2 million = expected prevalence of 504
- Number of PwMND known to the Association approx 350 – how do we increase this figure?
- Complexity and fragmentation of statutory services - pathways need joining up and streamlining
- Inequity in provision – mapping revealed pockets of excellence and “black holes”
- Understanding and meeting the needs of BME communities
- Small volunteer base (and not representative of London’s diverse population)

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The London Team

- Senior Team Leader (London) – 3 year post
- London has been split into 3 areas for RCDA coverage – North & West; East; South
- Volunteering Development Co-ordinator
- 3 Care Centre Co-ordinators

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Broad aim of the project

- PwMND in London have timely and equitable opportunity of access (as close to their homes as possible) to appropriate, high quality care. Including:
  - Access to an MDT
  - Appropriate palliative/end of life care
  - Respiratory and nutritional support
  - Equipment
  - Support from the Association

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Challenges

- Paucity of data on people with MND
- Commissioners do not know what they're spending on MND associated services
- Education of GPs and primary care
- Overcoming the "small numbers" argument
- Not being a "Cinderella service"
- User involvement
- Palliative care

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Challenges cont'd…

- Fragmented pathways
- Services reliant on good will rather than as a result of commissioning decisions
- Continuing care
- Housing issues
- Multi-agency/cross-boundary working
- "What are key workers?"
- Direct provision v strategic influencing

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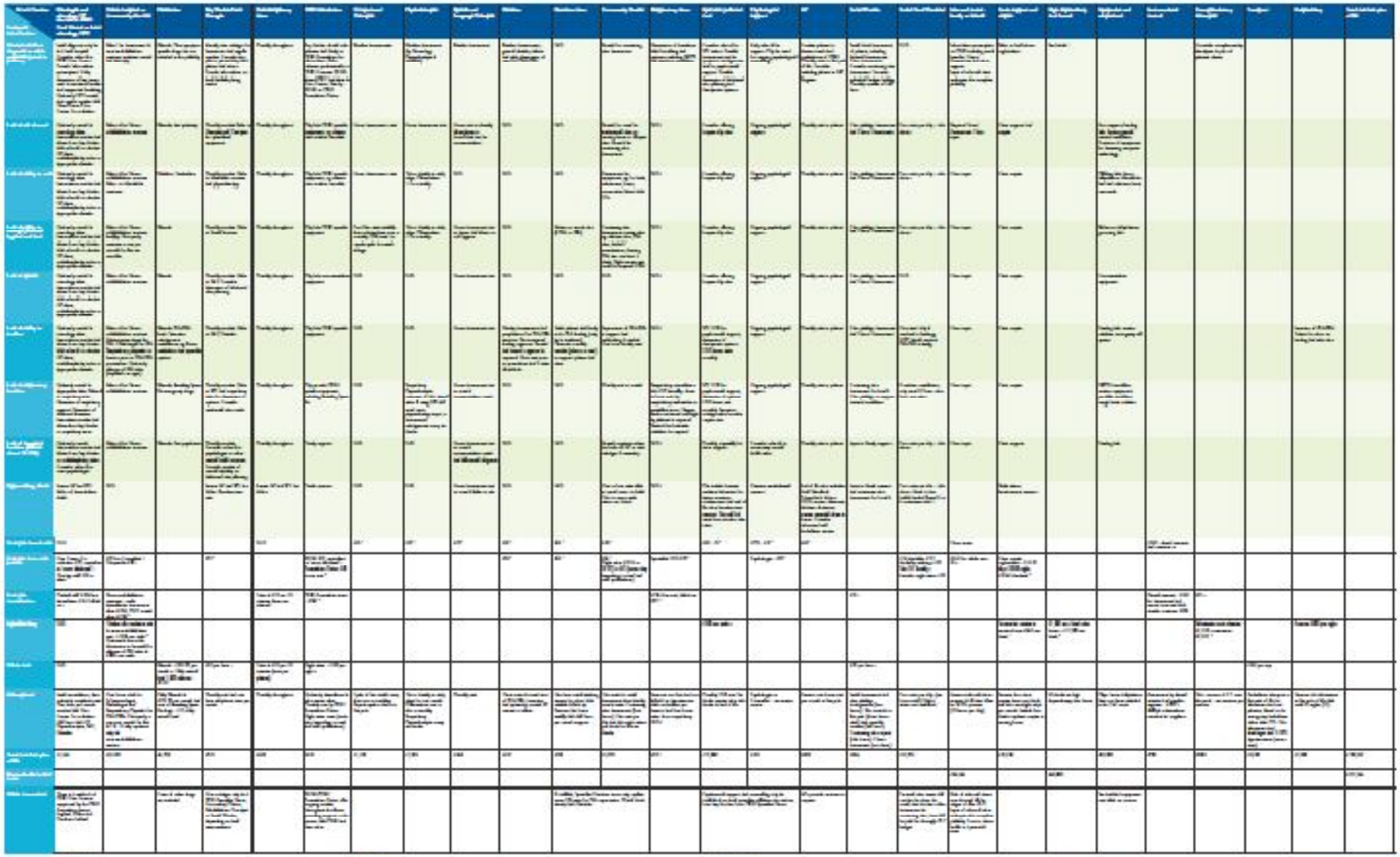
MND Year of Care Pathway

MOTOR NEURONE DISEASE ASSOCIATION



M·A·C

Partnership working

- Neurological Commissioning Support (NCS) in Wandsworth
- Putting service users (and clinicians) at the heart of neurology commissioning
- Aims of project include:
  - Auditing current services against NSF
  - Setting up local neurological network
  - User, carer and voluntary sector engagement
  - Co-ordination of services, clearer pathways
  - Case co-ordination and key working
  - Developing a staff training strategy
  - Promoting personalisation

More joint working

- Wheelchair partnerships
- London Neurological Alliance
- Close working with hospices e.g. St Joseph's

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Successes

- Increasing number of MDTs for MND
- NE London neurological Special Interest Group
- Barts and the London Care Centre
- Increase in the number and diversity of volunteers coming on stream
- Respiratory pathways improving in E London

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So, how *can* we improve services?

- Co-ordinated pathways of care
- MDT/multi-agency working
- Key workers
- Timely access to equipment (inc home adaptations)
- Timely nutritional and respiratory support
- Improvements with Continuing Care process
- Support for carers
- Improved awareness amongst HSCPs
- Specialist palliative and appropriate End of Life care
- Greater engagement with commissioners

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Contact details

- **Michelle O'Brien** – Senior Team Leader (London)
  07501 682 098
  michelle.obrien@mndassociation.org

- **MND Connect**:
  08457 626262 (for PwMND and carers)

  01604 611870 (for HSCPs)
  mndconnect@mndassociation.org

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