Health Checks for people with Intellectual Disabilities: Are they working?
The English Experience

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Overview

- Why is it important?
- What do we know so far?
- What happens next?
- Where does this lead to?

Definition of Intellectual (learning) Disabilities in England

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

(Valuing People 2001)

Changes in the population of people with Intellectual disabilities

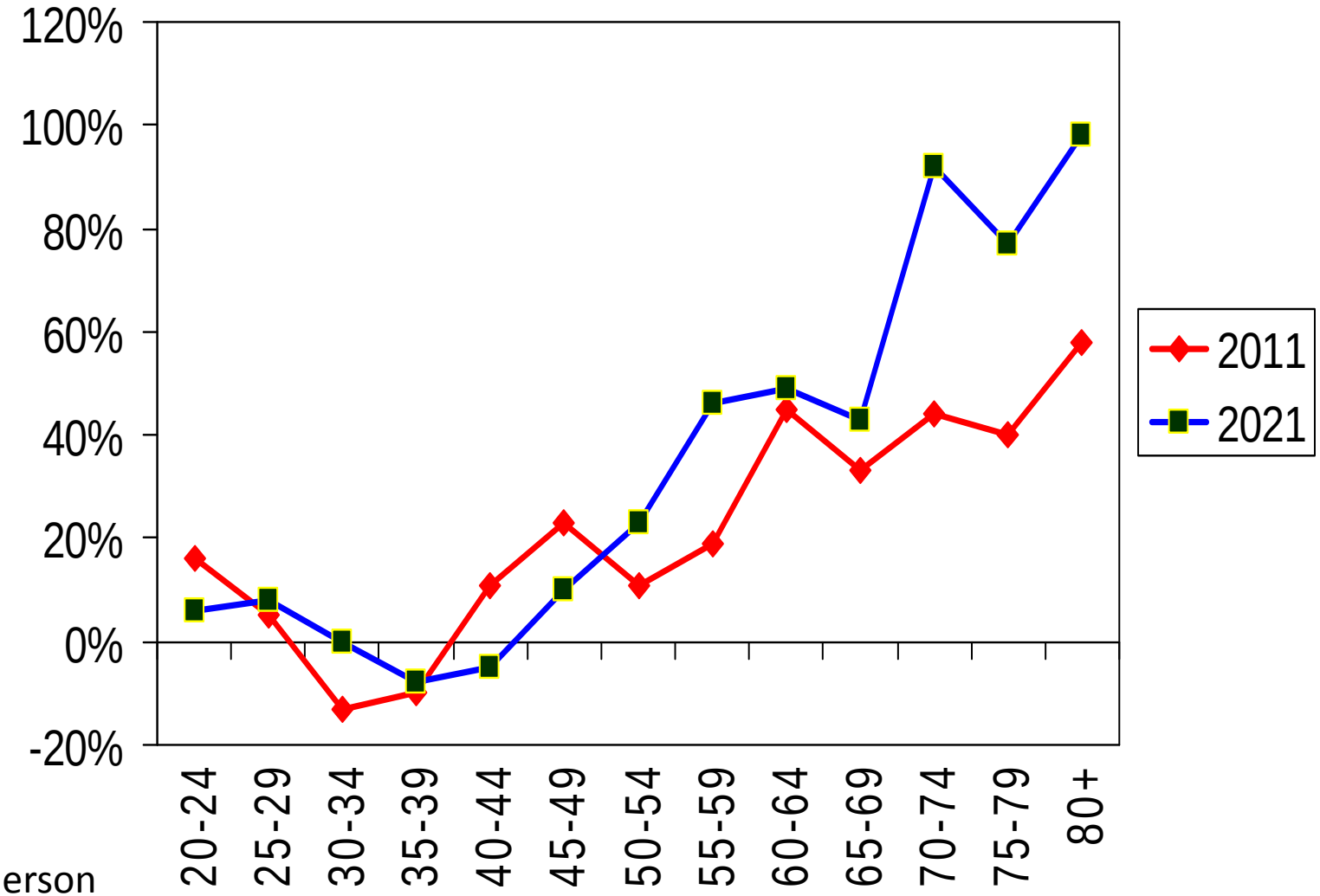
- Incidence
  - No reliable information
- Prevalence
  - Increased life expectancy
    - In general
    - Children with severe and profound disabilities
    - Older adults
- Age structure
  - Ageing of the baby boomers

Prevalence of Intellectual Disabilities

	Children	Adults
Denmark	4.0/1000[1]	?
England	4.7/1000[2]	4.2/1000[3]

[1] . LS, Jensen H, Skov L. (2007)
[2]. Glover, Evison and Emerson, (2010)
[3]. Emerson et al. (2010)

Predicted Change in Administrative Population in England



Source: E. Emerson

The Prevalence of Specific Diseases and health conditions

- Cancer
  - Lower than general population but higher incidence of Gastrointestinal cancer (12-18%).
- Coronary Heart Disease
  - A leading cause of death with increasing rate (14-20%)
- Respiratory Disease
  - Higher rates than the general population (46-52%)
- Dementia
  - Higher prevalence compared to general population (22% versus 6% aged 65+)

The Prevalence of Specific Diseases and health conditions

- Epilepsy
  - 20 times higher than for the general population
  - Resistant to drug treatment
- Mental health and challenging behaviour
- Higher prevalence in children and adults
- Sensory impairment
  - 40% reported to have hearing impairment
  - More likely to have visual impairment
- Physical Impairments
  - Non-mobility associated with seven fold increase in death

What is Health?

'Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.'

(WHO 1948)

What is Health Inequality?

Differences in health status between social groups ‘which are unnecessary and avoidable but, in addition, are also considered unfair and unjust’

(Whitehead 1992)

What is Health Inequality?

- *'Equity in health implies that ideally everyone should have a fair opportunity to attain their full health potential, and more pragmatically, that none should be disadvantaged from achieving this potential, if it can be avoided.'*

  (WHO 2000)

Determinants of health inequalities

- Socio-Economic, Cultural and Environmental Conditions
  - Housing, employment, poverty
- Genetic and biological factors
- Personal Health Risks and Behaviours
  - Diet, exercise, substance use and sexual health
- **Access to and the Quality of Health Care**

Confidential Inquiry into the deaths of people with intellectual disabilities

Reviewed :

- All known deaths of people with intellectual disabilities
- From 5 Primary Care Trust in England
- From 1st June 2010 – 31st May 2012.

233 adults with intellectual disabilities

14 children with intellectual disabilities

58 comparator cases.

www.bristol.ac.uk/cipold/fulfinalreport.pdf

The cohort of people with intellectual disabilities

- Age 4-96.
- Over half (58%) male.
- Most (93%) single.
- Most (96%) White British.

40% had mild intellectual disabilities
31% moderate intellectual disabilities
21% severe intellectual disabilities
8% had profound and multiple intellectual disabilities.

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Age at death

Median age at death for males was 65 years

Men with intellectual disabilities died on average 13 years earlier than men in the general population.

Median age at death for women was 63 years

Women with intellectual disabilities died on average 20 years earlier than women in the genera population.

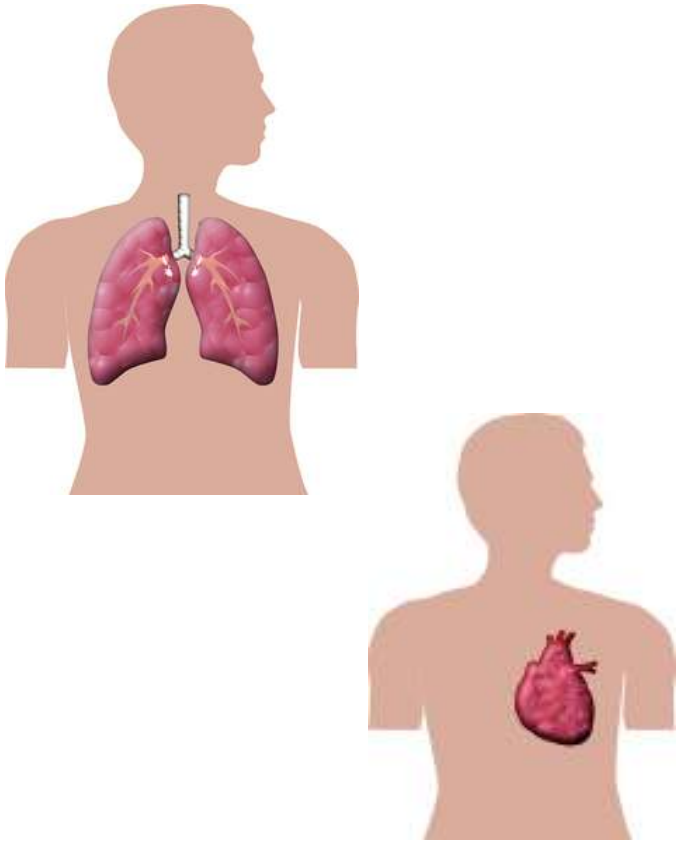
www.bristol.ac.uk/cipold/fulfinalreport.pdf

Causes of death

- Immediate cause of death
- Underlying cause of death
- Any other diseases, injuries, conditions or events that contributed to the death, but were not part of the direct sequence leading up to the death.

www.bristol.ac.uk/cipold/fulfinalreport.pdf

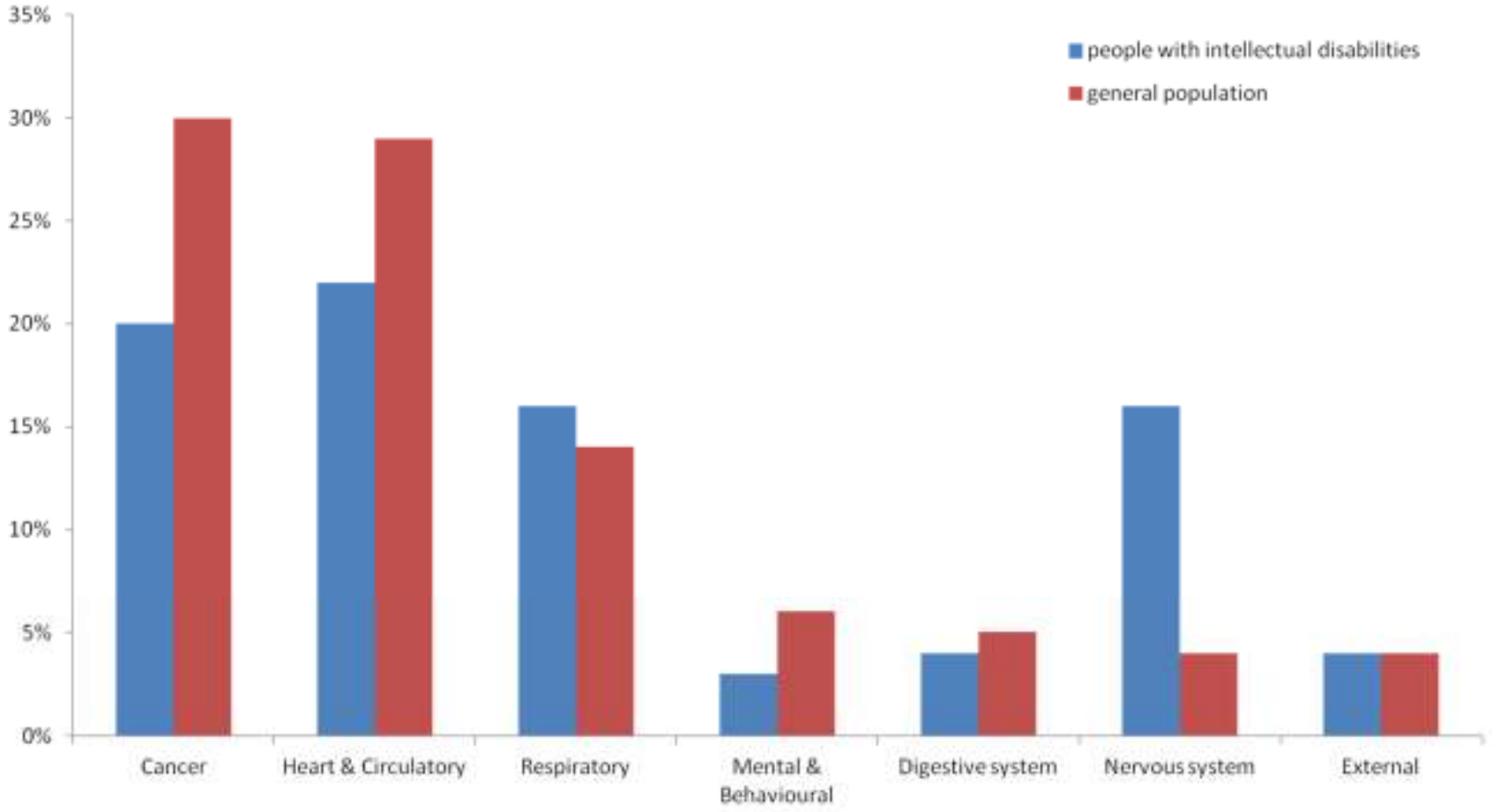
Immediate causes of death



- The most common immediate causes of death in people with intellectual disabilities were:
- respiratory problems (34%)
- heart and circulatory disorders (21%).

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Underlying causes of death among people with intellectual disabilities and in the general population (Helsop et al. 2013)



Deaths amenable to good quality healthcare

Significance of:

- age
- severity of intellectual disabilities
- underlying cause of death
- if had a significant partner/friend.

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Premature deaths

- 42% of deaths considered to be premature
- Younger people more likely to have premature death

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Most common reasons for premature deaths

- Problems with assessing or investigating the cause of illness.

  This affected 41% of those whose illness was reported to a medical practitioner .

- Problems with treating a person's illness.

  This affected 42% of those diagnosed with an illness.

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Avoidable deaths

Preventable mortality

All or most deaths from that cause could be avoided by public health interventions in the broadest sense.

Amenable mortality:

All or most deaths from that cause could be avoided through good quality healthcare.

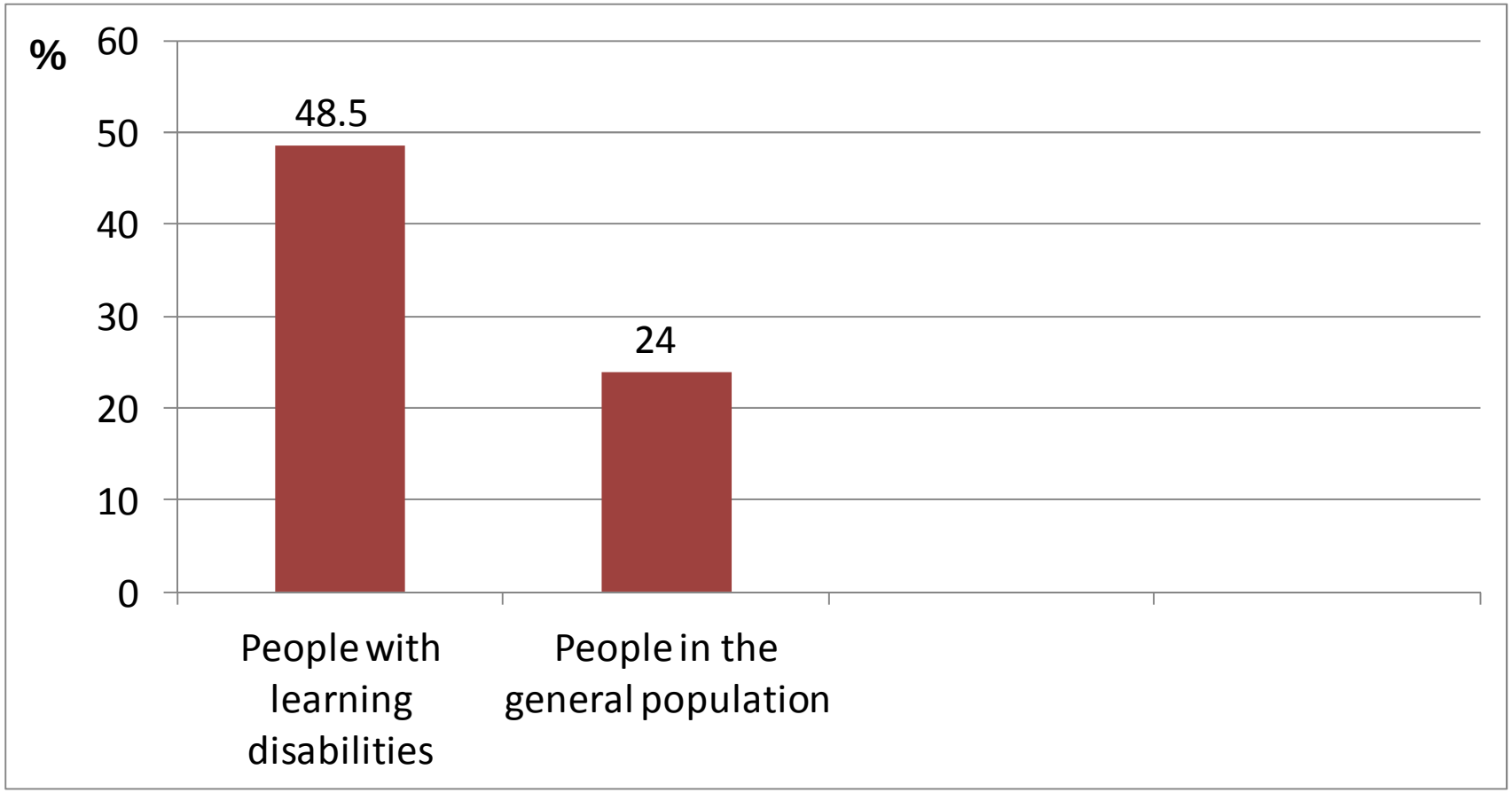
27.5%

12%

9%

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Total avoidable deaths



www.bristol.ac.uk/cipold/fulfinalreport.pdf

Most common problems with diagnosis

Type of problem with diagnosis	%
Problems with the investigations	40
Died with undiagnosed significant illness	33
Concerns of person, family or paid carers not taken seriously enough	25
Problems with referral to specialist	19

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Issues related to the delays in the care pathways

- A lack of reasonable adjustments to help people to access healthcare services.
- A lack of coordination of care across and between different disease pathways and service providers.
- A lack of effective advocacy for people with multiple conditions and vulnerabilities.

www.bristol.ac.uk/cipold/fulfinalreport.pdf

Special Health Checks

- Represent a ‘reasonable adjustment’
- Effective in identifying unmet health needs
- Introduced in England as an additional (enhanced service) in 2008 as annual service.

Effectiveness of Health checks

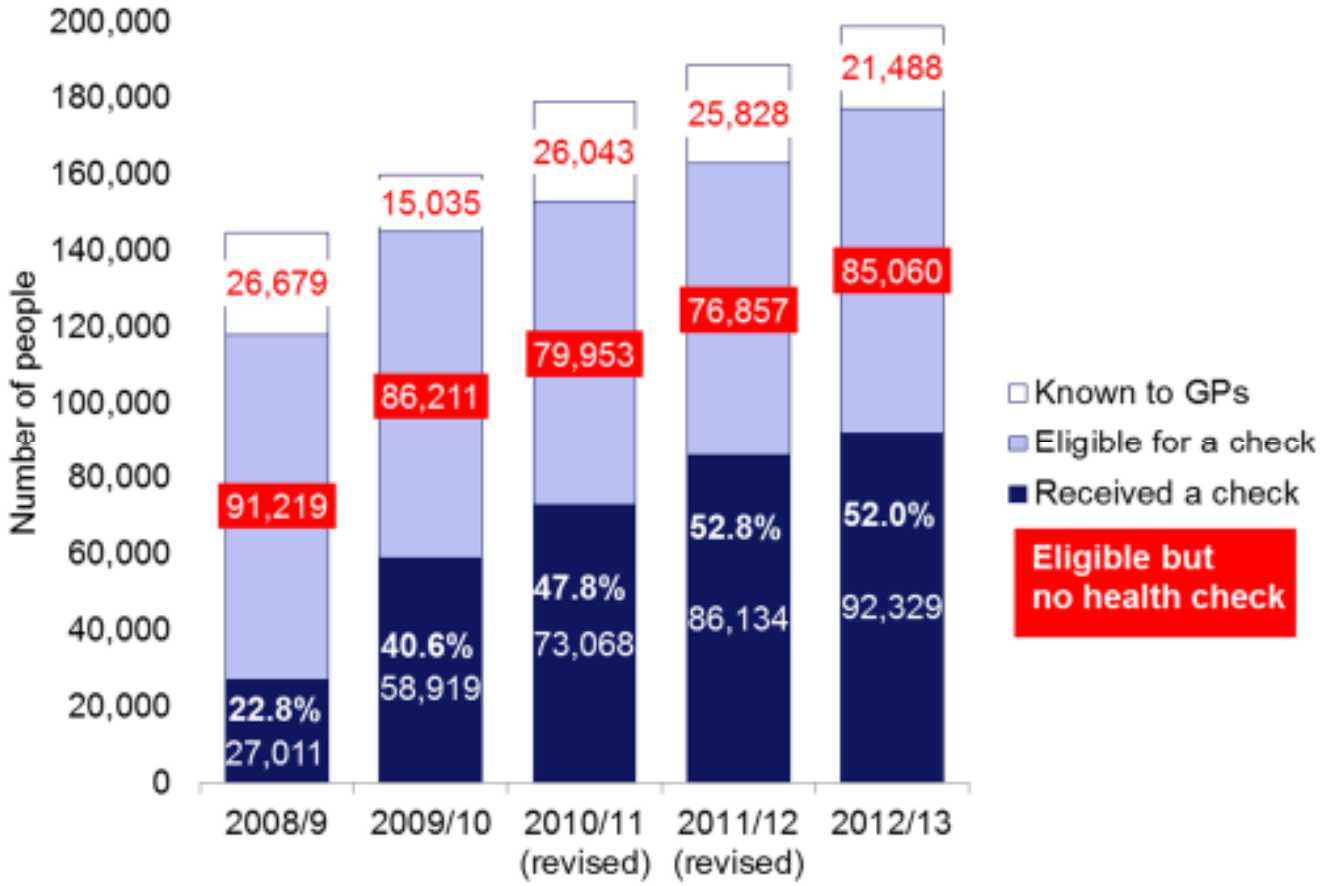
- Identify previously undetected health conditions in 51% to 94% of patients.[1] [2]
  - Conditions identified include conditions such as cancer, heart disease and dementia.
- Effective in promoting health actions to address identified health needs[3] [4] [5]
  - Include referrals to services such as dentists, opticians, dieticians.

[1] Baxter et al. 2006. [2] Cooper et al 2006. [3] Beange et al. 1995, [4] Lennox et al. 2008 [5] Carlsen et al. 1994

Uptake of Health Checks 2008/9-2012/13 (%change from previous year)					
	2008/9	**2009/10**	**2010/11**	**2011/12**	**2012/13**
Number of people who received a health check	27,011	58,919 (+118%)	73,068 (+24%)	86,023 (+18%)	92,329 (+7.2%)
Number of people identified as eligible to receive a health check	118,230	145,130 (+23%)	153,021 (+5%)	162,945 (+6%)	177,389 (+8.8%)
% of identified eligible people who received a health check	23%	**41%** (+78%)	**48%** (+18%)	**53%** (+11%)	**52%** (-0.8%)

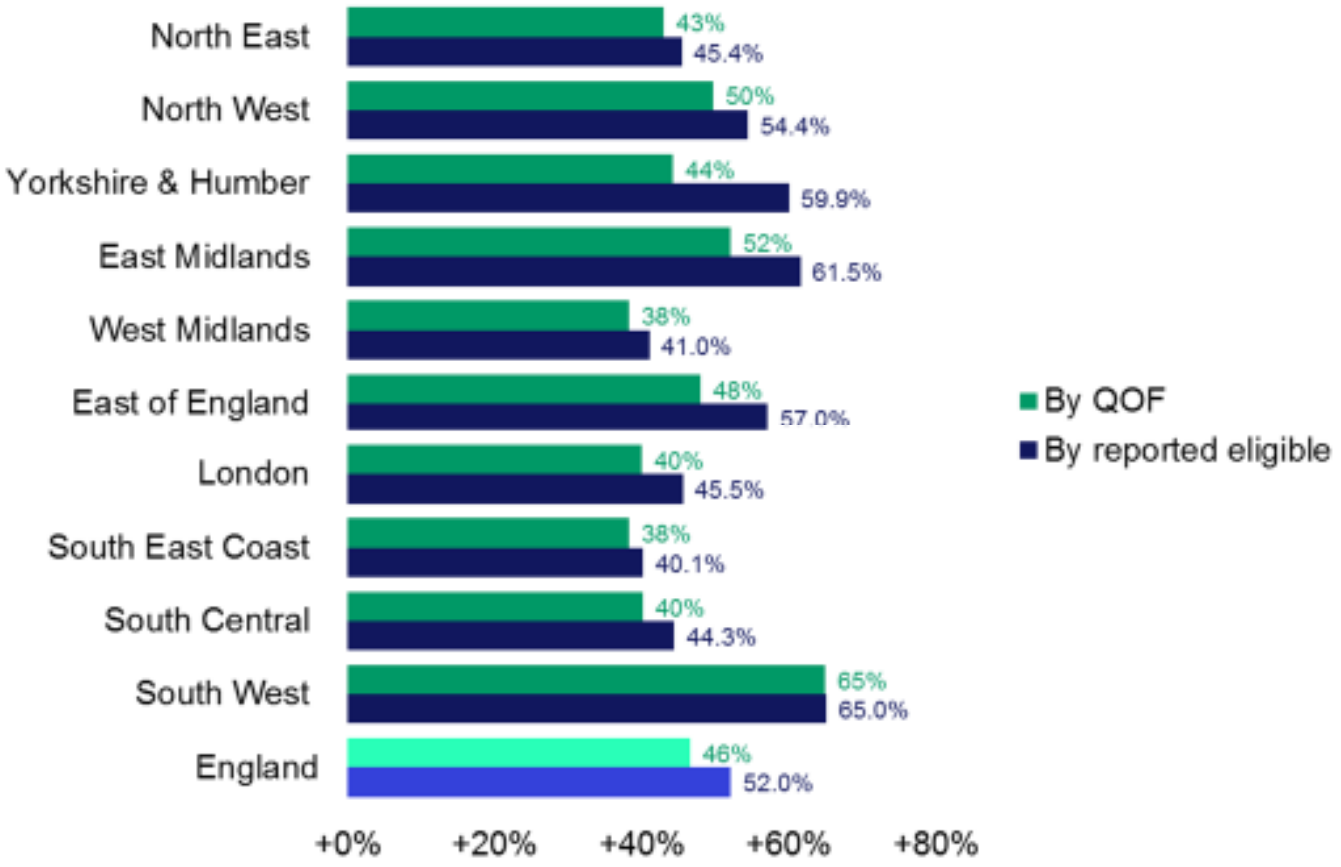
www.ihal.org.uk/annualhealthchecks

All known to GPs



Annual ID Health Checks 2012/13
www.ihal.org.uk/annualhealthchecks

Health checks as % of QOF number vs ‘Coverage’



Annual ID Health Checks 2012/13
www.ihal.org.uk/annualhealthchecks

Health checks: Screening Processes linked to QOF incentives

	Record by health check for 2011		
	No health check [2358] (%)	Health check [1674] (%)	P-value
Blood Glucose Test	495 (21)	600 (35.8)	P<0.001
Renal Function	772 (32.7)	865 (51.7)	P<0.001
TFT	623 (26.4)	759 (45.3)	P<0.001
Blood Pressure	1301 (55.2)	1493 (89.2)	P<0.001
Cholesterol	621 (26.3)	766 (45.8)	P<0.001
Urine analysis*	210 (8.9)	447 (26.7)	P<0.001

*Screening for protein, blood and glucose

ID specific health check Processes

	Record by Health Check for 2011		
	No health check [2358] (%)	Health check [1674] (%)	P-value
Health Action Plan (annual)	9 (0.4)	342 (20.4)	P<0.001
Visual Assessment (annual)	74 (3.1)	743 (44.4)	P<0.001
Hearing Assessment (annual)	45 (1.9)	883 (52.7)	P<0.001
Bowel Assessment (annual)	5 (0.2)	94 (5.6)	P<0.001
Mobility Assessment (ever)	169 (7.2)	693 (41.4)	P<0.001
Behaviour Assessment (ever)	38 (1.6)	142 (8.5)	P<0.001
Self-neglect Assessment (annual)	7 (0.3)	19 (1.1)	P<0.001
Housing Dependency (ever)	300 (12.7)	504 (30.1)	P<0.001
Feeding Assessment (annual)	1 (0.04)	5 (0.3)	P=0.09

Equal access to health care

‘providing the right service at the right time in the right place’

(Rogers et al. 1999)

What Next?

- From April 2014 GPs will be asked to keep a record of ALL patients with intellectual Disability (will include those under the age of 18 years).

What Next?

- From April 2014 Annual Health Checks will be offered to Adolescents (14-17 year olds)

What Next?

- Development of a National Audit for Intellectual Disability
- Feasibility pilot will be completed in March 2013
  - Aim is to determine the feasibility and scope of a future national clinical audit of physical and mental healthcare for adults with learning disabilities
  - focused on primary and secondary healthcare services

http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/auditoflearningdisabilities/learningdisabilities.aspx

Primary Care Audit Standards

Criteria	% Pilot ID Population	% England General Population
Patients had an annual health check in the preceding 12 months	52%	52%
Patients with an active diagnosis of epilepsy, on treatment , had their seizure frequency recorded in the preceding 12 months	57%	90.9% (2012/13)[1]
Patients with an active diagnosis of epilepsy, on drug treatment who had been seizure-free in the preceding 12 months	33%	62.1% (2012/13)[1]
Patients on the mental health register (QOF) had a record of alcohol consumption in the preceding 12 months	80%	82% (2012/13)[1]
Percentage of patients with learning disability on the mental health register (QOF) who have a record of: BP	93%	84.9% (2012/13) [1]
Patients on the mental health register (QOF) had a record of: cholesterol	73%	42.4% (2012/13) [1]
Patients on the mental health register (QOF) who have a record of: blood glucose	65%	66.9% (2012/13) [1]

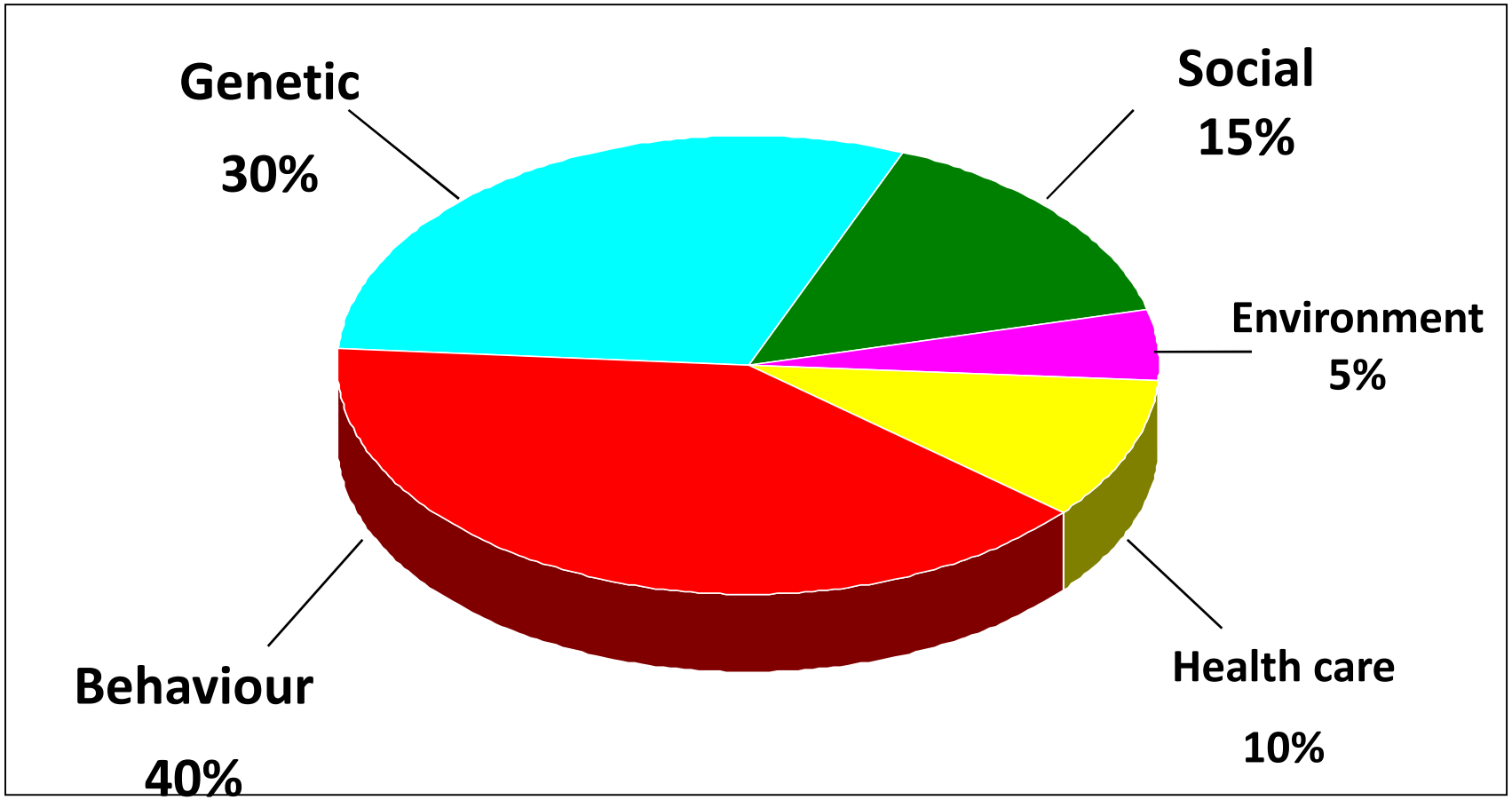
Primary Care Audit Standards

Criteria	% Pilot ID Population	% England General Population
Patients with Downs' Syndrome had a record of blood TSH in the preceding 12 months	63%	83% (2012/13) [1]
Influenza vaccine uptake in over 65 years of age	42%	74% (2012)[2]
Influenza vaccine uptake in at risk group between 6 years to 65 years	68%	50.4%
Breast screening uptake	36%	77% (2012)[3]
Cervical Screening Uptake	24%	79% (2012)[3]

[1] http://qof.hscic.gov.uk/index.asp
[2] http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1195733756886#r1
[3] http://www.cancerscreening.nhs.uk/cervical/publications/cervical-annual-review-2012.pdf

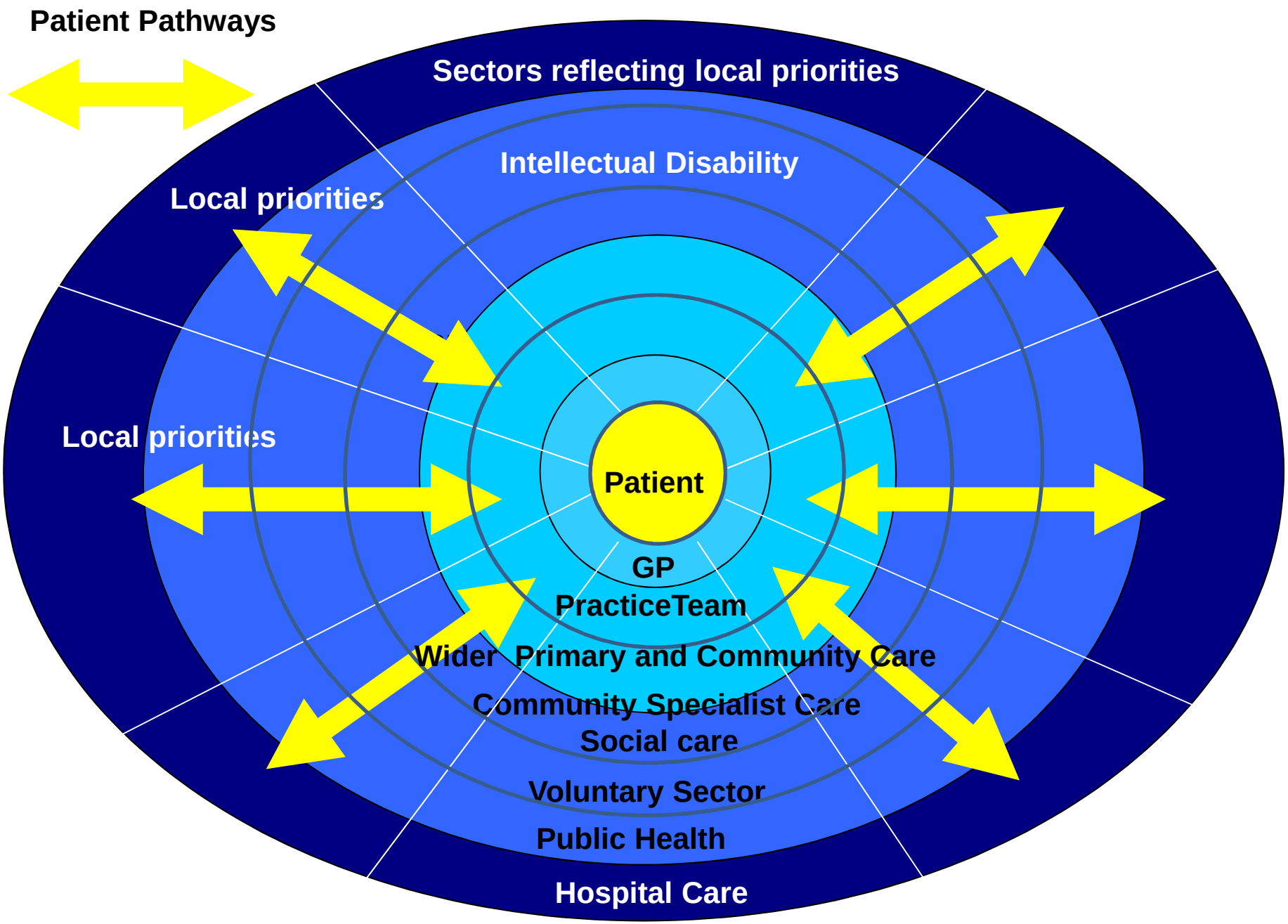
Where Next?

Determinants of Mortality (McGinnis, Williams-Russo et al. 2002)



An Integrated Neighbourhood Model

- Population - locally defined
- Practice list based
- Services move into neighbourhood settings
- Services wrapped around the patient
- Multi – disciplinary
- Single integrated record
- Single vision – local delivery
- Locally accessible



Integrated neighbourhood model

Any Questions?

Thank you

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Other associated conditions

- Oral Health
- Dysphagia
- Gastro-oesophageal reflux (GORD)
- Constipation
- Osteoporosis
- Obesity
- Diabetes
- Other Endocrine disorders