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GP Update:

Improving the health of People with Learning Disabilities



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Session objectives

Overview of the health profile of people with learning disabilities

- Including risk behaviours, comorbidities, and mortality

Healthcare issues

- Care coordination, transition
- Preventative interventions: Annual health checks, screening, flu
- Tips on how to feasibly deliver AHCs in reality
- Tips on reasonable adjustments

Resources



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Health profile of people with learning disabilities

- In 2011, there were ~1.2 million persons with learning disabilities in England
- 905,000 were adults (aged over 18 years)
- 530,000 were men, 375,000 were women
- ~170,000 were children on school registers (2.5%)

- There were considerably more people with learning disabilities in poorer households



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How many people are there in Yorkshire & the Humber with learning disabilities ?

| Yorkshire & Humber | Total population | Estimated number of persons with learning disabilities |
|--------------------|------------------|--|
| 2016 QOF | 5,830,400 | 31,000 |
| 2016 estimate | 5,425,400 | 117,000 |
| 2021 projection | 5,538,000 | 119,500 |
| 2026 projection | 5,656,100 | 122,000 |

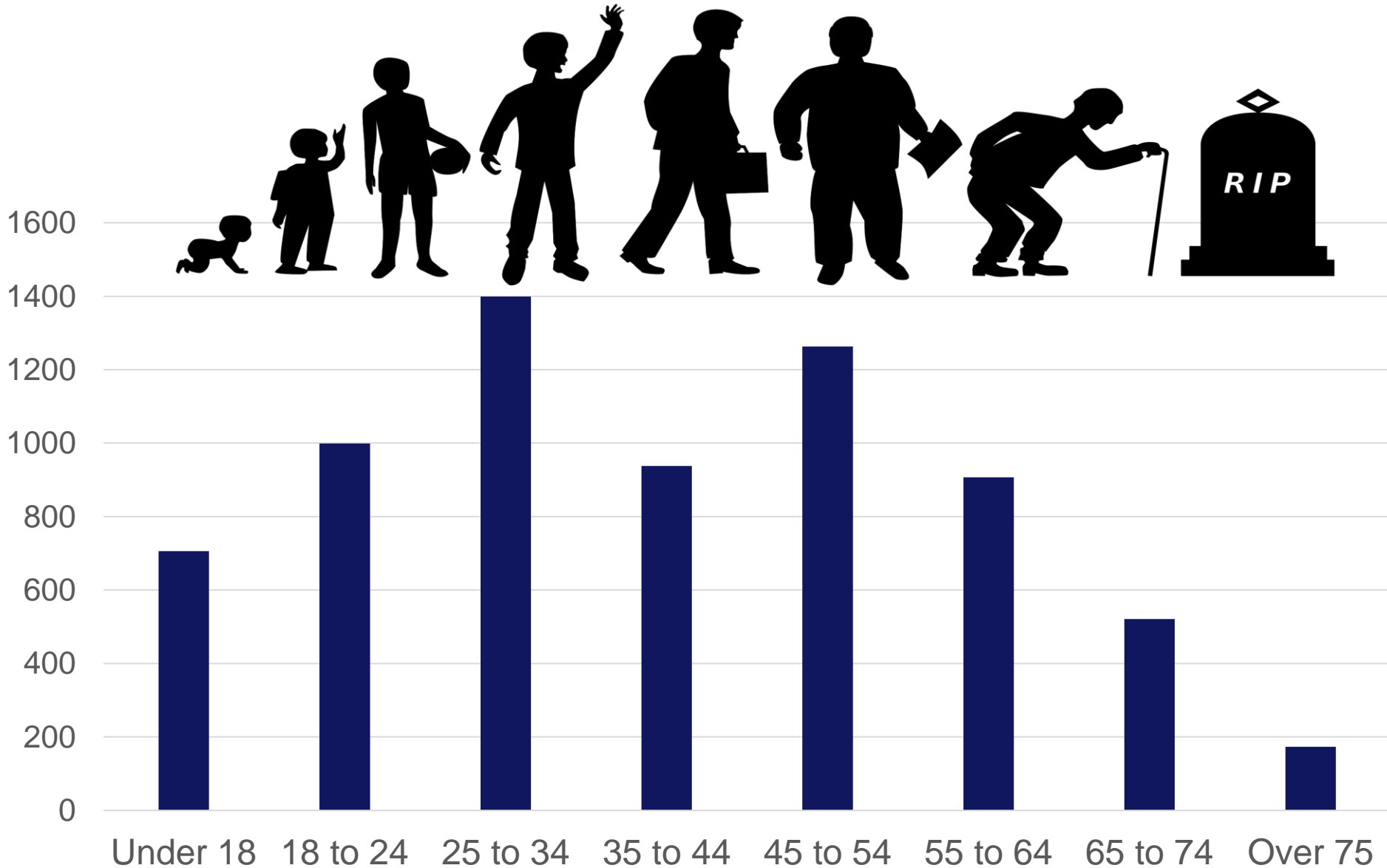
Population estimates based on LDO prevalence of 2.16%

QOF prevalence of **0.53%**.



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Age profile of people with learning disabilities in Yorkshire & Humber in 2016

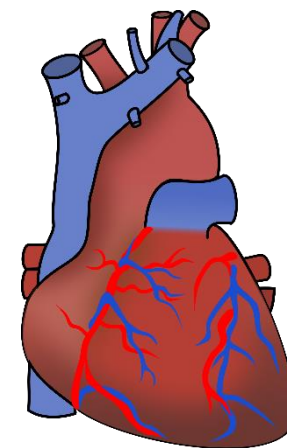
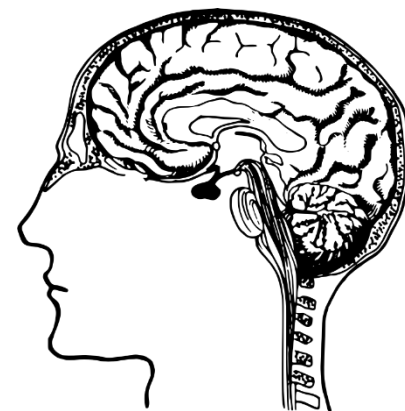




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Co-morbidities

| Health problem | How many times more |
|-------------------|---------------------|
| Epilepsy | 22.5 |
| Mental health | 7.6 |
| Dementia | 4.5 |
| Hypothyroidism | 2.6 |
| Diabetes (Type 2) | 1.8 |
| Kidney disease | 1.6 |
| Heart failure | 1.5 |
| Stroke | 1.4 |
| Asthma | 1.3 |
| Hypertension | 0.9 |
| Cancer | 0.8 |





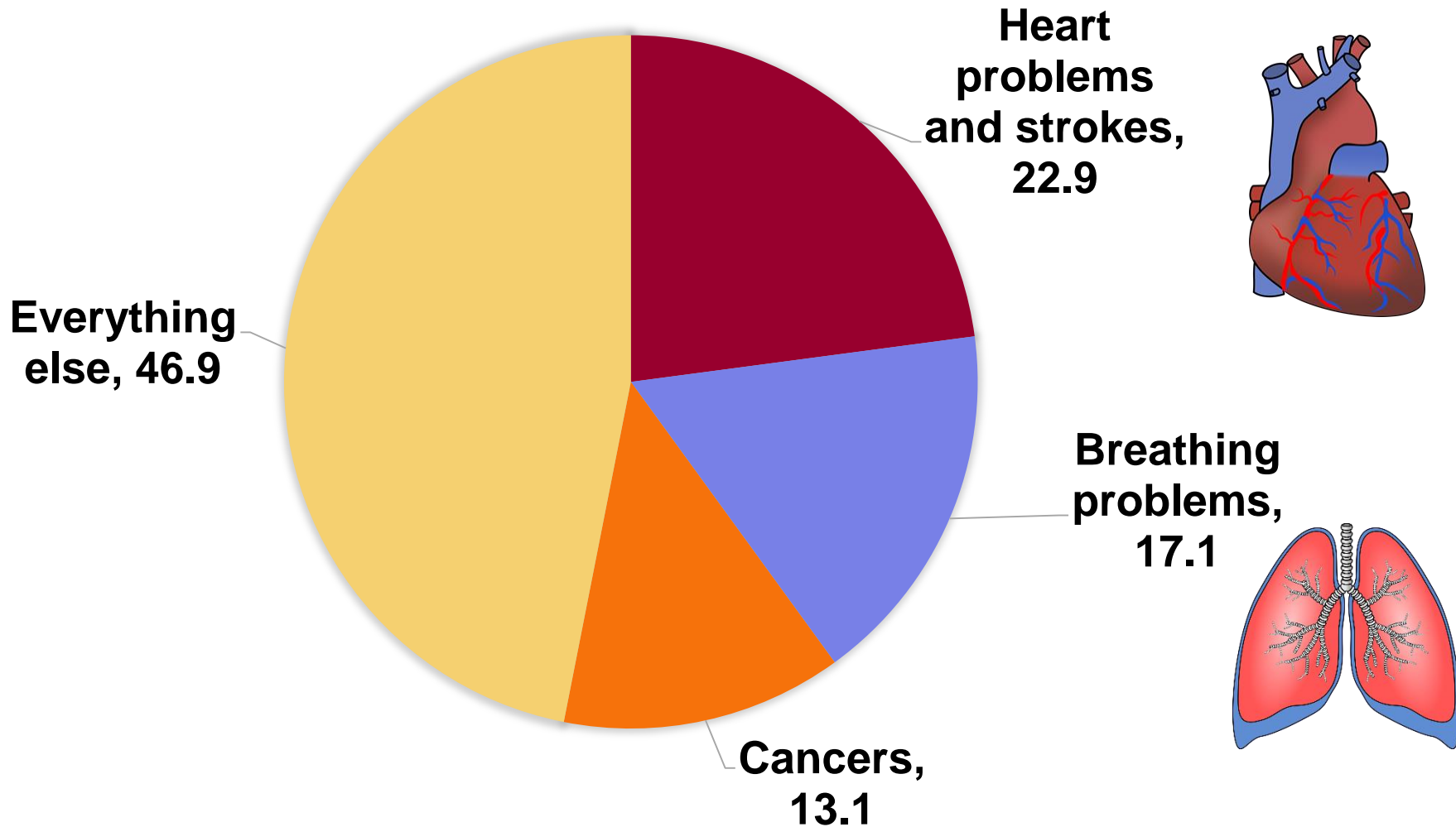
| | Male | Female |
|---|------------|------------|
| Compared to people without learning disabilities how many times more likely are people with learning disabilities to die? (Standardized mortality ratio) | 3.0 times | 3.4 times |
| How long can people with learning disabilities live on average? (Life expectancy) | 63.8 years | 66.7 years |
| How much shorter is the length of life for people with learning disabilities? | 19.8 years | 20.2 years |
| | | |



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What are the common causes of death in people with learning disabilities?

PROPORTION OF DEATHS (%)





People with learning disabilities have a higher chance of dying from...

| Causes | Chance of death x |
|--------------------------|----------------------|
| Epilepsy | 34.4 |
| Lung disease | 21.8 |
| Flu and chest infections | 7.7 |
| Strokes | 3.3 |
| Heart disease | 2.2 |



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Premature mortality

Confidential Inquiry into Premature deaths in People with Learning Disabilities (CIPOLD), 2011 reported:

❖ **42%** of deaths considered to be premature

The most common reasons for premature death were problems with:

- ❖ **investigating or assessing the cause of illness**
- ❖ **treating their health problems**





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Premature mortality

BMA(2014) reported:

Excess morbidity and premature mortality predominantly result from *a failure to adequately diagnose, treat and prevent comorbid physical health conditions* in people with a learning disability.

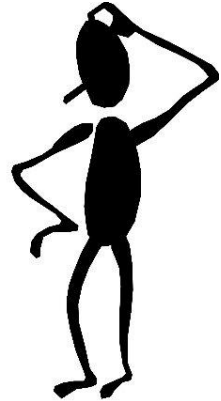
In the worst cases, people receive less than optimal medical care and unnecessarily have unmet health needs.

Research by Mencap (2012) found cases of DNAR orders being inappropriately applied to people with LD





Contributing factors

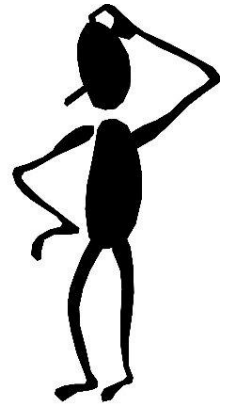


- ❖ **Lack of awareness** of their health needs amongst primary care staff.
- ❖ **Lack of priority** given in the NHS generally
- ❖ Lack of **effective advocacy** for people with multiple conditions and vulnerabilities.
- ❖ Low take-up for national cancer **screening** programmes
- ❖ Low uptake of **immunisations**
- ❖ Increased risk of death due to **respiratory infections**



Contributing factors

- ❖ Lack of **coordination of care** across and between different disease pathways and service providers.
- ❖ Problems with **identifying needs**
- ❖ Difficulty providing appropriate care in response to **changing needs**.



LEARNING POINT:

TRANSITIONS are often problematic!

Your patient may have ongoing communication, speech & language, occupational therapy needs, etc... even in adulthood, that may be accessible via your Community Learning Disabilities Team



Contributing factors

❖ ***Diagnostic overshadowing***

❖ ***Delays or problems with diagnosis or treatment***

LEARNING POINTS:

Mental health problems are often overlooked and therefore untreated in people with learning disabilities. This includes common mental health problems such as depression and anxiety disorders, or dementia in Down's syndrome.



Contributing factors

❖ **Overmedication**

➤ **Stopping over medication of people with a learning disability, autism or both (STOMP)**

PwLD more likely to be given psychotropic medicines ... for 'challenging behaviour'

30,000 to 35,000 adults with a learning disability given psychotropic medicines, when they do not have an appropriate medical indication for them.

Children and young people are also prescribed them.

Dangers with overmedication and long term use.

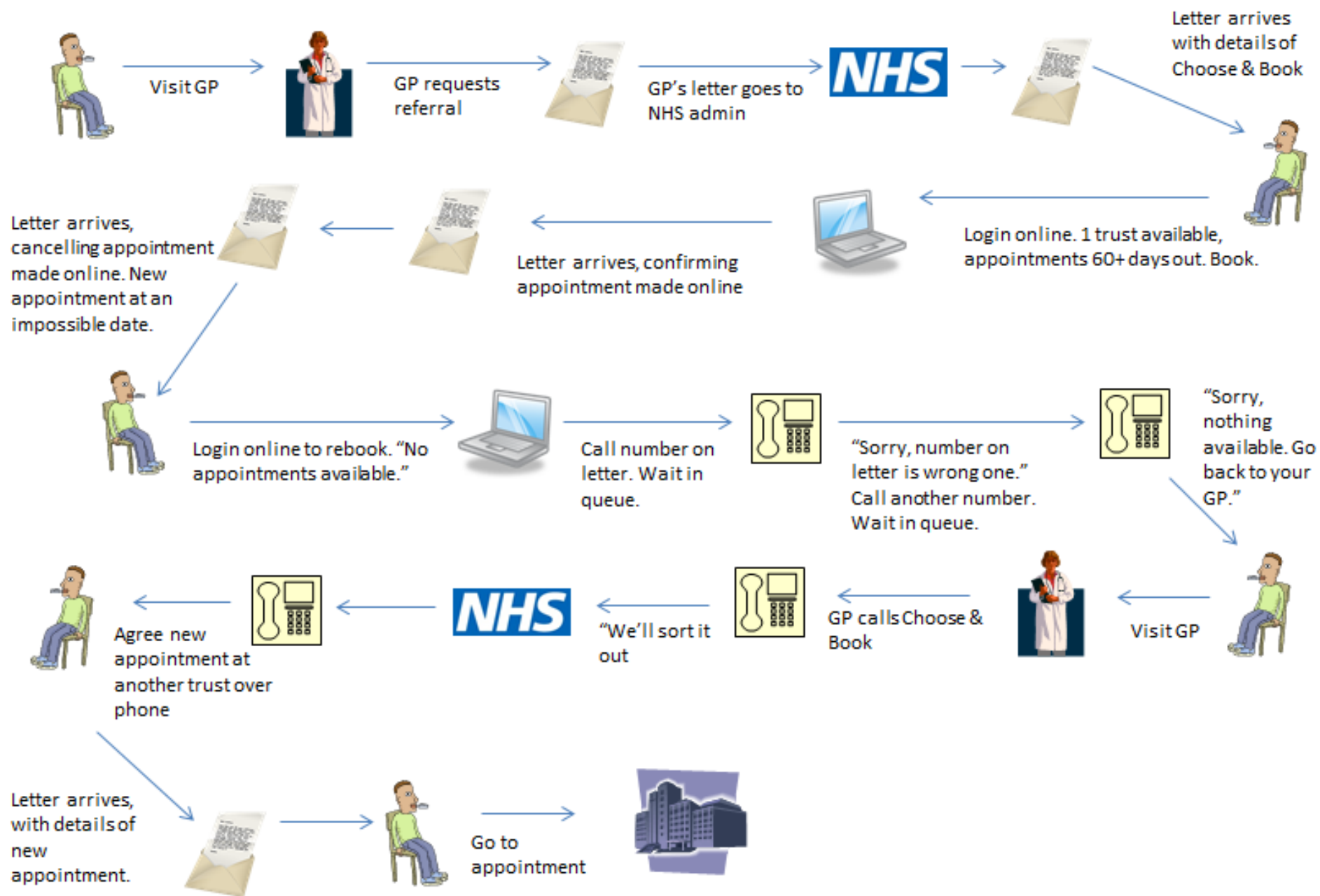




Lack of *reasonable adjustments* to help people to access healthcare services.

- Inflexible organisational policies, procedures and practices
- E.g. many deaf people or those with a hearing impairment were forced to make contact with their GP using a method that was not the best for them
- 90% of GP surgeries in Wales did not offer suitable alternatives for making appointments.

Choose and Book: How it Works (Patient Perspective)





Other contributing factors

- ❖ **Communication problems** during the consultation.
- ❖ **Lack of time** to conduct an adequate consultation.
- ❖ Patient inhibitions because of previous **negative encounters**



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What can we learn from the tragic Jack Adcock / Bawa Garba incident?



LEARNING POINTS:

Down Syndrome associated with hypo-immunity

Signs and symptoms of disease may be more muted and not 'classic'.

Co-morbidities/polypharmacy need to be considered



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ANNUAL HEALTH CHECKS

Not to be confused with NHS Health Checks

£140 for each patient aged 14 or over who received a compliant health check

Series of questions that cover a range of issues from sex, disease screening to vulnerability.

Linked to Health Action Plans

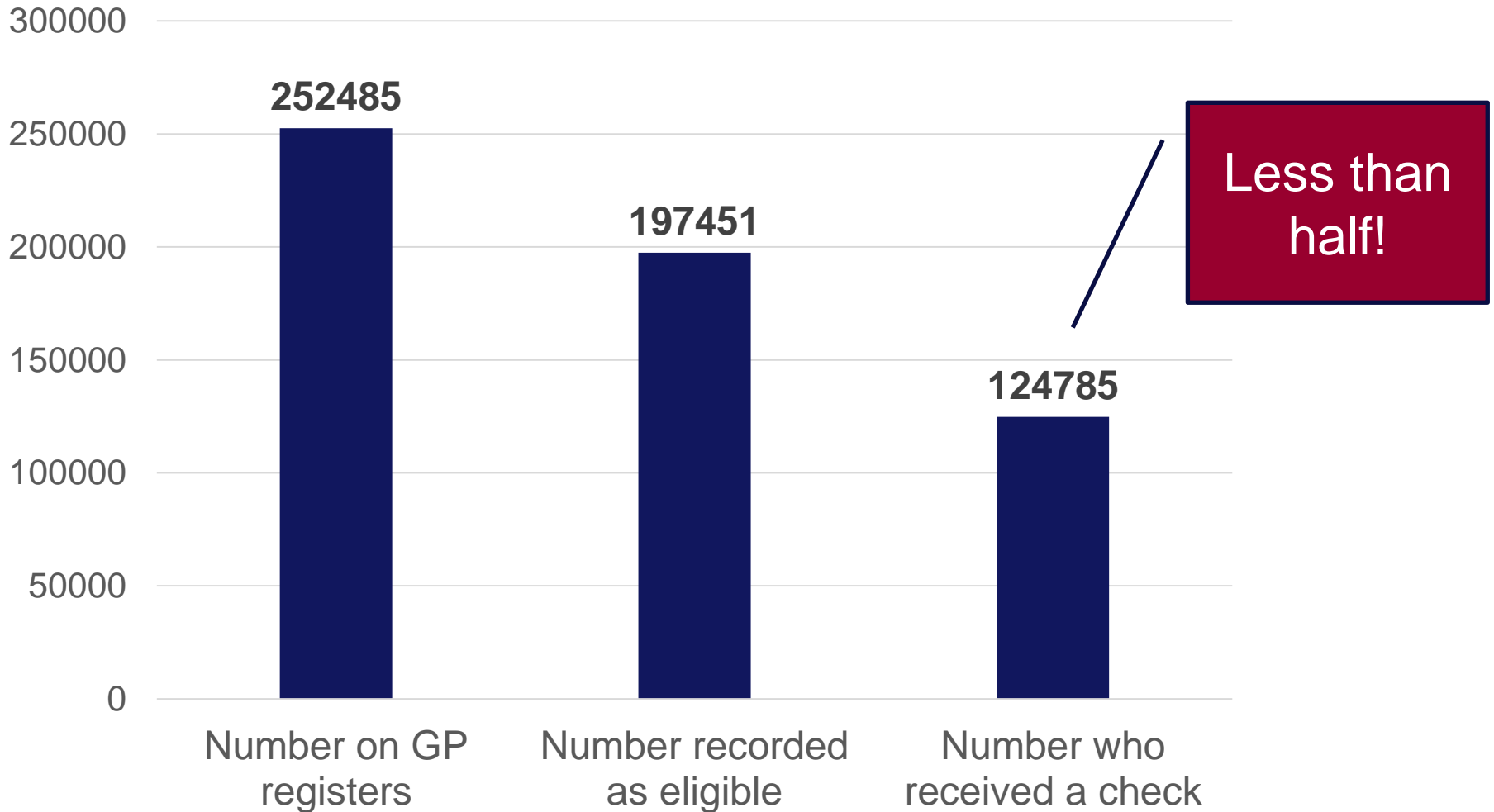
Important tool for detecting issues

28 of 33 Barnsley practices registered to deliver this

RCGP has a useful toolkit on how to do it



Uptake of Annual Health Checks





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Opportunity for health promotion

(Unhealthy) Lifestyle behaviours common:

- Lack of physical activity
- Poor diets
- Alcohol, Tobacco and Drug use
- Sex





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Other health issues to think about

Dental health

Eye checks

Hearing

Feet

Screening tests

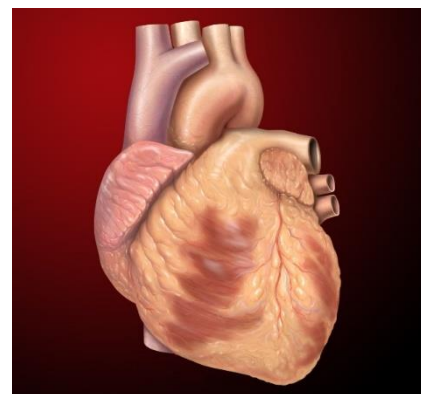
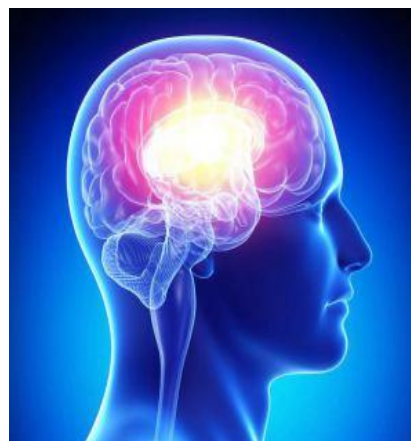
Flu jabs





Longer term health problems to watch out for

- Epilepsy
- Mental health
- Dementia
- Thyroid problems
- Diabetes
- Heart disease & strokes
- Dysphagia
- Asthma / respiratory problems
- Mobility





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Consider safeguarding

They are vulnerable adults to exploitation, abuse, domestic violence and assault.

Lack of 'stranger danger' or problem-solving skills

Lack insight into dangerous/risky situations

Older PwLD may no longer have family carers to look out for them.

Issues around mental capacity

Coordination of care – Who's taking responsibility?



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Tips on reasonable adjustments we can make...



Learning Disabilities Register

- ✓ **Get them on your Learning Disabilities Register.**
You can't make reasonable adjustments if you haven't identified them.
- ✓ Flag it on your systems and use it to alert and remind practice staff of the need to make adjustments.
- ✓ **Don't forget the carers**, who often ignore their own health needs. They're entitled to flu jabs too!



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Communication

They often have difficulties communicating pain, emotional distress, bowel trouble or indeed any other sensation

LEARNING POINTS:

They may understand more than they can express.

They may communicate with Makaton but it does not mean they are deaf!

Be patient! It's like communicating in a different language...



Communication

Parents/carers are useful interpreters and they know what's normal/not normal!

✓ Use pictorial aids

Wong-Baker FACES® Pain Rating Scale



©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org
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Ready made symbols and pictures for communication can be downloaded from www.widget-health.com



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Issues with procedures

They may be very fearful of medical procedures and examination!

- ✓ Familiarise them with procedures and clinical settings in advance.
- ✓ Use dolls, etc... to demonstrate the procedure
- ✓ Have you got topical anaesthetics for painful procedures?
- ✓ Are there any videos you can show them?



<https://www.youtube.com/watch?v=c4gVGmllu7c>



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Accessible Information Standard (2016)

Requirement!

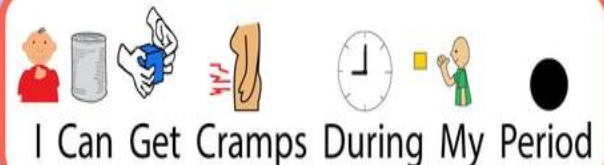
Make sure the information we
give is accessible and
understandable.

Use EASY READ leaflets

Use pictorial communication
aids like social stories

I Can Get Cramps During My Period

Able2LEARN





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Appointments

Remember they often have multiple health appointments to attend...

- ✓ Help them to plan appointments in advance if possible
- ✓ Be flexible with providing them appointments

Do they need more time with the GP?

- ✓ Book a double appointment
- ✓ Book the last slot of the clinic session





Other Reasonable Adjustments

Their needs may be very specific.

- ✓ If they need reasonable adjustments can they make arrangements with someone nominated in the practice for this (e.g. senior receptionist or practice manager in advance)

They may be unsettled in the waiting room (claustrophobic, too much stimulation/noise, boring, etc...)

- ✓ Have them wait outside (e.g. in the car) & make an arrangement with the receptionist to call them in?
- ✓ Get the first appointment or end of the day when it is quieter?
- ✓ Arrange a home visit in advance?



Improving communication

Medical information is often confusing for the patient/carer

- ✓ Provide easy read if possible
- ✓ Write it down
- ✓ Use pictures, large print and simpler words
- ✓ Let them audio record the consultation
- ✓ Allow in their carer to help them remember things



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Continuity of Care

This is key!

- ✓ Can we encourage them to see a GP they like and try to book in to see the same one most of the time. They will get familiar with you.
- ✓ Give them a printed copy of their medical summary. Especially useful as they may have to deal with many different health professionals
- ✓ Give them an up to date list of medicines



Complexity

These are complex patients. Don't expect to know everything especially for rarer conditions. The parent/carer may know more about the condition than you do.

That said, even people with rare conditions can get common ailments which the GP can help with. Common ailments are more common, than rare effects of any condition/disease.

- ✓ Be patient – if it is a complicated issue it may take time and several visits to sort.
- ✓ Are you the wrong professional/service provider for the issue they have? Signpost to the right ones



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Challenging behaviour?

Don't assume it is just 'bad' behaviour.

Do a functional analysis:

ANTECEDENT – What were the circumstances/triggers that led to...

BEHAVIOUR – What was the behaviour demonstrated

CONSEQUENCE – What was the consequence of the behaviour

Some PwLD may have very fixed routines and any deviation causes extreme distress that manifests as 'bad behaviour'.

Don't expect them to fit to your way of doing things...



Parents & Carers

- They are not the enemy but valuable allies!
- Remember that being a carer is extremely demanding and exhausting, and many may be ‘on the edge’
- They also know the PwLD well, what’s normal, what’s not, how they communicate, how they express pain etc... Many of them do have the patient’s best interest at heart. So trust them!
- At the end of the day you may only see the ‘challenging’ patient once, but the parent/carer has to deal with it all the time...



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Reminder of pitfalls to avoid

Have you considered alternative diagnoses /
co-morbidities?

Are you missing depression?

Are you overmedicating?

Are you missing diet & constipation?



At the very least...

- Get them onto the GP register for learning disabilities**
- Give them a summary of their medical records**
- Give them a printout uptodate list of their medications**
- Do medication reviews regularly (at least once a year)**
- Give them their flu jabs (both carers and patients)**
- Try and give them an annual health check**
- Try and get a health action plan done**



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**Spread the message and
raise awareness with your
staff and colleagues**



Resources

- ❖ NHS Professional resources for STOMP:

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/professionals/>

- ❖ RCGP Annual Health Check toolkit

<http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx>

- ❖ www.widget-health.com

Provides free (and for purchase) communications material.

- ❖ Having an operation at Sheffield Children's Hospital video

<https://www.youtube.com/watch?v=c4gVGmllu7c>

- ❖ <https://www.specialiapps.org/en-us/special-stories.html>

App to help create pictorial 'social' stories that can be used to explain a procedure or expected behavior, etc...

See the   **Person** 
Not the  **Disability**