

# Consultation report: Learning disabilities

Consultation period: 13 April 2023 – 15 May 2023

Date of Indicator Advisory Committee meeting: 06 June 2023

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## Learning disabilities: annual health action plans

IND2022-129: The percentage of patients on the learning disability register aged 14 or over, who received a learning disability health check and a completed health action plan in the preceding 12 months.

### Rationale

People with a learning disability often have poorer physical and mental health, and are more likely to die of preventable illness ([Learning from Lives and Deaths - people with a learning disability and autistic people 2021](#)). An annual health check and action plan can help to identify concerns at an early stage.

### Summary of consultation comments

Comments were received from 7 stakeholders. Most noted the potential positive impact on health outcomes and opportunity to improve under-treatment of people with a learning disability. One stakeholder noted that health checks however are only one component of reducing inequalities. Stakeholders report variation in the completion and recording of action plans, with discrepancy between the number of health checks reported and action plans completed. It was noted that the action plan should also be shared with relevant parties.

There were some concerns raised around the accuracy of the learning disability register, upon which this indicator depends.

Most stakeholders did not feel there would be unreasonable additional workload implications or additional inconvenience for patients. The action plan should be completed alongside the existing annual health checks and medication reviews.

One stakeholder noted that people who lack capacity will benefit from a health check and therefore the personalised care adjustments may need to be considered. In addition, it was noted that people with a learning disability may need reasonable adjustments for care and communication.

One stakeholder asked that the accompanying guidance specify the inclusion of CVD checks and end of life planning if appropriate.

## **Considerations for the advisory committee**

The committee is asked to consider:

- Stakeholder reports of the discrepancy between the number of health checks reported and action plans completed.
- Concerns around the accuracy of the learning disability register.
- Whether personalised care adjustment codes for people who decline an action plan should continue to be included.

## Learning disabilities: ethnicity recording and annual health action plans

IND2023-152: The percentage of patients on the learning disability register aged 14 or over, who:

- received a learning disability health check and a completed health action plan in the preceding 12 months and
- have a recording of ethnicity.

### Rationale

People with a learning disability often have poorer physical and mental health, and are more likely to die of preventable illness ([Learning from Lives and Deaths - people with a learning disability and autistic people 2021](#)). An annual health check and associated action plan can help to improve the health of people with a learning disability by identifying health concerns at an early stage. This indicator also requires a recording of ethnicity: increasing levels of premature mortality are noted in people with a learning disability from minority ethnic family background.

### Summary of consultation comments

Most comments on IND2022-129 also apply to this indicator.

In relation to the added requirement for recording of ethnicity, stakeholders were supportive of the potential to improve health inequalities. There were no concerns that this would involve unreasonable additional workload implications or additional inconvenience for patients.

It was queried whether children under 14 should be included given the existence of health inequalities at all ages.

### Considerations for the advisory committee

The committee is asked to consider whether the age range for this indicator (and the previous indicator) should be lowered. This would require an alternative register.

## Appendix A: Consultation comments

ID	Stakeholder organisation	Indicator	Comment	Response
1	NHS England	IND2022-129	<p>Will help to support primary care with health action plans so that they are seen as a 'must do' rather than a 'nice to do' by practices. Although usually it is done and not recorded or seen with the same priority. However, if we want to make a real difference to patient outcomes, the health action plan is crucial. Keen for this to have as much stability as possible.</p> <p>If data collection and sharing will increase from its QOF inclusion that will help better understanding of what is happening nationally.</p> <p>There should be minimal increase in workload as already an expectation that doing an annual health check should also include thinking about the 'what next' for the patient.</p> <p>This incentivisation would be very patient centred – it is the key part which can make a difference to outcomes for individuals and where more focus could helpfully be applied.</p>	Thank you for your comment.
2	NHS England	IND2022-129	In relation to Page 4: "Personalised care adjustments should be considered to account for situations where the patient declines the health check or action plan".	Thank you for your comment.

ID	Stakeholder organisation	Indicator	Comment	Response
			<p>For most patients who lack capacity, it will be in their best interest to have an annual health check. There is evidence that poor adherence to the principles of the Mental Capacity Act has a negative impact on the physical health of autistic people and those with a learning disability (see page 49 (Learning from Lives and Deaths - people with a learning disability and autistic people 2021)).</p>	
3	NHS England	IND2022-129	<p>For information, Health action plans are already part of the primary care contract DES (direct enhanced service).</p> <p>Data tells us that there is a discrepancy between the number of annual health checks completed and health action plans completed.</p> <p>We are aware of some Initiatives where health action plans are being linked to social prescribing and the outcomes are good.</p> <p>A good HAP is the ‘so what’ of the annual health check and can positively reduce health inequalities being experienced through consistent follow up and support by encouraging inclusion in screening programmes, imms and vacs programmes, support around diet and exercise, optical, dental and audiology check-ups, follow up with specialist services and so on.</p>	<p>Thank you for your comment.</p> <p>A note has been added to the guidance document that the plan should be shared with other relevant health and social care professionals with clarity around timescales and who is responsible for actions.</p>

ID	Stakeholder organisation	Indicator	Comment	Response
			<p>The indicator being linked to QOF will not necessarily have any additional impact on people receiving a health action plan.</p> <p>We would recommend some explanatory wording for clinicians to remind them of the importance of ensuring that the health action plan has been distributed to relevant parties with clarity on who is responsible for each action and timescales.</p> <p>Serious Case Reviews reporting on premature mortality have identified circumstances wherein health action plans were developed but not distributed to individuals accountable for actions, thus rendering them ineffective in improving outcomes and addressing under-treatment (Serious Case Review: James. October, 2015 page 44).</p>	
4	Primary Care Cardiovascular Society	IND2022-129	<p>This is an important indicator and by including in QoF should improve access and reduce health inequalities for people with learning difficulties as all of primary care would have to offer this service.</p> <p>It would be important to specify patients have a CVD check within this, and an EOL plan if required.</p>	<p>Thank you for your comment.</p> <p>A note has been added to the guidance document signposting to NHS England guidance on the provision of health checks and use of a national template.</p>
5	Royal Mencap Society	IND2022-129	<p>We support the development of the indicator with regard to learning disability annual health checks. However, quality of annual health checks varies considerably. We suspect in</p>	<p>Thank you for your comment.</p>

ID	Stakeholder organisation	Indicator	Comment	Response
			some cases a regular appointment is recorded as an annual health check – in our experience surveying people with a learning disability nationally, often the number of people reporting they have had a health check is much lower than the number reported by NHS England (based on GP data).	
6	Royal Mencap Society	IND2022-129	Practices and systems are monitored as to the percentage of patients on the learning disability register who have received an annual health check. This is important and we would not advocate for its removal. However, we feel this should always be accompanied by monitoring of how the learning disability register is being developed within the practice and specifically, how people are added to the register. Currently only around 1/5th of the estimated population with a learning disability in England are on the register. Without also monitoring that the numbers on the register are increasing, we worry that it could create a perverse incentive to keep the register numbers low.	Thank you for your comment. The indicator guidance document and validity assessment have been updated to reference the difference between the QOF register and estimated prevalence. A link to NHS England guidance on improving the quality of the register has also been added.
7	Royal College of General Practitioners	IND2022-129 and IND2023-152	The RCGP is calling for an immediate suspension of QOF during the current crisis with the need of a review to identify 5-10 indicators that have the greatest evidence of impact on patient outcomes that could be retained once QOF is re-introduced. Over the	Thank you for your comment. As part of the changes to the GP Contract 2023/24, NHS England have committed to review QOF in its current form with the aim of making it more streamlined and focussed.



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			<p>years, QOF has become painfully detailed in terms of reporting, both clinically and administratively, causing increasing frustration for GPs. This can divert the attention of GPs away from the patients sitting in front of them in consultations. It is also likely to be driving an increase in the number of unnecessary appointments, which may be more about ticking a box to reach a target rather than looking at what is needed by the individual patient.</p>	
8	Royal College of General Practitioners	IND2022-129 and IND2023-152	<p>General comments from the Special Interest Group for Learning Disability – the group totally and unanimously agree with the essential nature of annual health checks to all adults with LD/Autism to prevent the increased preventable mortality and morbidity in this population.</p> <p>The group acknowledges the significantly increased risks of mortality and morbidity affecting those of this minority living in social deprivation due to inadequate financial, educational and housing provision and how these factors affect those of ethnic minorities more.</p> <p>The group believes QOF assessments of efforts made to record all patients with LD/autism registered with a practice would lead to health gain. Special considerations</p>	Thank you for your comment.

ID	Stakeholder organisation	Indicator	Comment	Response
			<p>need to be given to the homeless and prison population which include a population with more than 2.5% incidence of LD.</p> <p>Future funding must accept the need to match the content of annual health checks with the expectations of patients and their carers particularly evidenced in the guidelines offered by expert groups e.g., Downs Association. Primary care AHC's are of greatest benefit if they assess the social circumstances of patients, and this is particularly relevant to patients in Ethnic minorities.</p>	
9	Diabetes UK	IND2022-129 and IND2023-152	<p>We welcome the proposal to move the indicator, i.e. the percentage of patients on the learning disability register aged 14 or over, who received a learning disability health check and a completed health action plan in the preceding 12 months into the QOF. Prevalence of diabetes in people with a learning disability is unknown, but research suggests higher rates of diabetes in people with learning disabilities than the general population. However, we know there is under recording of people with a learning disability on GP registers is extremely poor with only 0.46% of the population recorded on the GP register as having a learning disability.</p>	<p>Thank you for your comment.</p> <p>The indicator guidance document and validity assessment have been updated to reference the difference between the QOF register and estimated prevalence. A link to NHS England guidance on improving the quality of the register has also been added.</p>

ID	Stakeholder organisation	Indicator	Comment	Response
			<p>In addition, we know from the research literature and numerous reports that there is a lack of effective systems to identify people with learning disabilities in hospital so health care staff were unaware that people might need such adjustments to access healthcare. The most recent LeDeR report, concurs with the earlier findings that a major contributory factor into premature and avoidable death is a delay in diagnosis and treatment and poor care coordination. This indicator will hopefully act as a lever to increase uptake onto the learning disability register and increase the health checks and completed health action plans.</p> <p>References: NHS Digital, 2017 LeDeR, 2022</p>	
10	Diabetes UK	IND2022-129 and IND2023-152	<p>We know people with learning disabilities are less likely to participate in screening for diabetes. Annual health check can detect conditions such as type 2 diabetes and therefore help ensure people access the right treatment and support to effectively manage their condition. Annual health checks also help identify any reasonable adjustments GPs (which are required under the 2010 Equality Act) can make to improve a person's diabetes care which we know from the research</p>	Thank you for your comment.

ID	Stakeholder organisation	Indicator	Comment	Response
			<p>evidence needs to improve. Diabetes is one of the leading causes of emergency ambulatory care admissions in the UK and there is emerging evidence that this maybe be due to poor management in primary care.</p> <p>We also know uptake of health checks by people with learning disabilities remains low and people with learning disability are less likely to be offered appropriate diagnostic investigations or treatments in a timely manner. It is important appropriate reasonable adjustments for care and communication, such as longer appointment times, appointment letters In Easy Read and calm waiting areas are implemented to help people with learning disabilities access mainstream health care services. These are detailed in the guidance document, NHS Right Pathway for Diabetes.</p>	
11	Diabetes UK	IND2022-129 and IND2023-152	<p>Annual health checks should be coordinated with medicine reviews and people’s reviews of diabetes wherever possible to reduce the number of visits to the service and inconvenience for the patient and carers. Information and training of healthcare staff to support the needs of people with learning disabilities is imperative.</p>	Thank you for your comment.
12	Diabetes UK	IND2022-129 and	<p>We concur with the findings of LeDeR that it is important the learning disability register</p>	Thank you for your comment.

ID	Stakeholder organisation	Indicator	Comment	Response
		IND2023-152	<p>differentiates between levels of learning disability to ensure person centred care. It is important too that carers and families are aware of the learning disability register, and we also wish to highlight that not everyone with a learning disability identifies as such (Watson,2002). Further work is needed to address these barriers to ensure effective implementation of these indicators.</p> <p>Personalised care adjustments should be considered to account for situations where the patient declines the health check or action plan to address any barriers and improve uptake.</p>	
13	The Challenging Behaviour Foundation	IND2022-129 and IND2023-152	<p>The Challenging Behaviour Foundation (CBF) believes these indicators will help to improve outcomes and address the under-treatment of people with a learning disability. Through our work with families of people with a severe learning disability and from data we know that people with a learning disability can struggle to receive an annual health check despite being entitled to one. Annual health checks are vital in ensuring that health issues are caught early and can be treated effectively – this is particularly crucial for people with a severe or profound and multiple learning disability who are non-verbal as health professionals are not always able to understand them when they try to convey</p>	Thank you for your comment.

ID	Stakeholder organisation	Indicator	Comment	Response
			health issues, and because of assumptions that symptoms or behaviours are a result of their learning disability rather than a sign of a medical issue or pain.	
14	The Challenging Behaviour Foundation	IND2022-129 and IND2023-152	The CBF does not believe there are unreasonable workload implications or data collection burdens linked to these indicators. It is crucial that accurate data is collected in order to improve outcomes for this group.	Thank you for your comment.
15	The Challenging Behaviour Foundation	IND2022-129 and IND2023-152	The CBF does not believe there are potential unintended consequences of these indicators.	Thank you for your comment.
16	The Challenging Behaviour Foundation	IND2022-129 and IND2023-152	These indicators will lead to positive differential impacts for people with a learning disability.	Thank you for your comment.
17	British Medical Association's General Practitioners Committee	IND2022-129 and IND2023-152	<p>In the opinion of BMA's General Practitioners Committee (England), QOF needs a wholesale review, and introducing new indicators and tinkering with old ones does not fit with the agreement to carry out a wholesale review made by NHSE and DHSC.</p> <p>In addition, when patients have multiple co-morbidities, single disease measures can be challenging. It would be helpful if NICE could advise whether there are conditions or medications for other conditions, that</p>	<p>Thank you for your comment.</p> <p>As part of the changes to the GP Contract 2023/24, NHS England have committed to review QOF in its current form with the aim of making it more streamlined and focussed.</p>

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			commonly occur with the single disease, that will result in a caution flag when co-prescribing, and if there are, provide guidance on whether to prescribe.	
18	British Medical Association's General Practitioners Committee	IND2022-129 and IND2023-152	With regards to moving from DES to QOF, as a principle, when considering whether outcomes measures should be at practice level or PCN level, we should consider which is the most appropriate scale of delivery. These seem appropriate for practice level delivery, in particular care of people with learning disabilities who benefit from continuity of care and building trusted ongoing relationships with the practice team.	Thank you for your comment.
19	British Medical Association's General Practitioners Committee	IND2022-129 and IND2023-152	In terms of inequalities, although physical health is important, there are inequities in terms of support in the community to meet wider human and wellbeing needs that is outside our gift. This has a big impact, including whether people have support that helps them to engage with our services. Using a QOF approach in delivering care to complex vulnerable people, who are likely to experience additional barriers to access, is unhelpful. It requires a QI approach of practice learning and adapting and personalising services, requiring time and investment in trying to understand and break down barriers. Practices should not be	Thank you for your comment.

ID	Stakeholder organisation	Indicator	Comment	Response
			penalised for trying and learning but still failing to hit the target.	
20	NHS England	IND2023-152	<p>Supportive of this indicator:</p> <p>Important to be able to see this data to allow systems to start to address the intersectionality inequalities.</p> <p>Crossover with wider requirement for primary care to complete ethnicity data so should be minimal additional work but an additional incentive.</p> <p>Appropriate to give additional focus to this area and evidence based.</p> <p>For information this is already an indicator in IIF contract with primary care.</p>	Thank you for your comment.
21	Royal Mencap Society	IND2023-152	<p>We support the development of the indicator in relation to ethnicity recording for people on the learning disability register. However, it is important to note that individuals can be added to the register at any age, including in childhood. LeDeR data also suggests that people with a learning disability from of Black and Asian ethnicities are likely to die younger, at least in part because they are more likely to encounter serious health inequalities at a younger age. Therefore, feel that for this indicator it would be beneficial to not stipulate those 14+. We are unable to comment on whether this would create any additional</p>	<p>Thank you for your comment.</p> <p>Following committee consideration, the indicator was amended to include all people with a learning disability, regardless of age.</p>



ID	Stakeholder organisation	Indicator	Comment	Response
			administrative burden, although in theory there is no reason why it should. The Race Equality Foundation have been campaigning for better monitoring of ethnicity and may be able to give further advice to the team on any specifics here.	
22	The Challenging Behaviour Foundation	IND2023-152	Collecting data on the ethnic background of people with a learning disability receiving an annual health check should improve outcomes for people from ethnic minority backgrounds as it will identify if people from particular backgrounds are less likely to receive an annual health check. If this is found to be the case then it will be possible to develop targeted solutions to improve access to annual health checks, which in turn will mean that health issues are identified earlier and can be treated with a higher likelihood of success. If it is the case that the premature deaths of people with a learning disability from ethnic minority backgrounds are linked to difficulties accessing annual health checks, then the data and actions resulting from this indicator should improve outcomes and address the under-treatment of these groups.	Thank you for your comment.
23	The Challenging Behaviour Foundation	IND2023-152	This indicator should lead to positive differential impacts for people from ethnic minority backgrounds who have a learning disability.	Thank you for your comment.

