Decision support tool for physical health (DST-PH): stratifying risks to reduce avoidable deaths in people with intellectual disability

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Abstract

Purpose – *People with intellectual disability die prematurely and from avoidable causes. Innovative solutions and proactive strategies have been limited in addressing this disparity. This paper aims to detail the process of developing a risk stratification tool to identify those individuals who are higher risk of premature mortality.*

Design/methodology/approach – *This study used population health management principles to conceptualise a risk stratification tool for avoidable deaths in people with intellectual disability. A review of the literature examined the existing evidence of causes of death in people with intellectual disability. A qualitative methodology using focused groups of specialist clinicians was used to understand the factors that contributed towards avoidable deaths in people with intellectual disability. Delphi groups were used for consensus on the variables for inclusion in the risk stratification tool (Decision Support Tool for Physical Health).*

Findings – *A pilot of the Decision Support Tool for Physical Health within specialist intellectual disability service demonstrated effective utility and acceptability in clinical practice. The tool has also demonstrated good face and construct validity. A further study is currently being completed to examine concurrent and predictive validity of the tool.*

Originality/value – *To the best of the authors' knowledge, this is the only study that has used a systematic approach to designing a risk stratification tool for identifying premature mortality in people with intellectual disability. The Decision Support Tool for Physical Health in clinical practice aims to guide clinical responses and prioritise those identified as at higher risk of avoidable deaths.*

Keywords *Mental health, Health inequalities, Challenging behaviour, STOMP, LeDeR, Mortality review*

Paper type *Research paper*

(Information about the authors can be found at the end of this article.)

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Background

More people with intellectual disability die prematurely and from preventable causes in comparison with the general population. Life expectancy for those with intellectual disability is on average 20 years shorter than the general population (Heslop *et al.*, 2014). The risk of premature mortality is further increased in those with a severe intellectual disability (Glover *et al.*, 2017; Arvio *et al.*, 2017). It is widely recognised that people with intellectual disability have a higher level of health needs, including mental health needs, which may place them at an increased risk of physical health decline (Cooper *et al.*, 2015). Many also need support to access health-care services due to difficulties such as communication, challenging behaviours and unstable mental health. Health-care professionals often rely on their observational skills and those of carers to identify underlying health needs (Heslop *et al.*, 2014). Furthermore, people often experience "diagnostic overshadowing" with their presentation attributed to their intellectual disability, resulting in misdiagnosis or delays in appropriate diagnosis and treatment (Emerson *et al.*, 2012).

In England, the UK Government commissioned a confidential inquiry (Heslop *et al.*, 2014), which examined 247 retrospective deaths of people with intellectual disability, identifying that 43% of the deaths were unexpected, 42% were thought to be premature and a significant proportion were potentially avoidable. It recommended a system-wide approach for review of deaths of people with intellectual disability to learn from and improve future health outcomes.

The Learning Disabilities Mortality Review (LeDeR) programme was commissioned by the Healthcare Quality Improvement Partnership on behalf of NHS England to review all deaths of people with intellectual disability. Annual reports from these reviews identified many systemic issues such as poor communication among health professionals, inappropriate use of the Mental Capacity Act, inappropriate use of "Do Not Attempt Cardio-pulmonary resuscitation", recording intellectual disability as a cause of death and diagnostic overshadowing (Heslop and Hoghton, 2018). The LeDeR reviews also identified late diagnosis and poor health care as key factors leading to avoidable deaths in this cohort (NHS England, 2018, 2021).

Although, reviews have identified themes and learning points, there remains a need for a systematic approach in reducing health inequalities and improving outcomes. A significant barrier to this is the lack of early identification of those who are at higher risk of avoidable deaths to ensure appropriate proactive interventions and care planning to improve health outcomes (Cooper *et al*, 2015; Heslop and Hoghton, 2018; NHS England, 2018). This highlighted the need for using population health management principles, with risk stratification at its core, to improve health outcomes in this population. Population health management is a process of establishing and improving the health outcomes of population groups through improved and co-ordinated care (McShane and Kirkham, 2020), thus reducing health inequalities by using a systematic method for improving health outcomes (NHS England, 2021).

A project task and finish group was established, with the aim of developing a process to proactively identify those with intellectual disability who were at risk of avoidable deaths. We considered avoidable deaths as deaths due to causes that were preventable or treatable. Our objectives were to:

- develop a risk stratification tool for using in the primary or secondary care to help identify those at higher risk of avoidable deaths;
- ensure the face and construct validity of the tool;
- pilot the tool in primary and secondary care for its acceptability and clinical utility; and
- develop a framework for meeting the needs of those who were at higher risk of avoidable deaths.

Methodology

The project was completed at a large NHS provider of primary and secondary mental health services in the Northwest of England, serving a population of approximately 1.2 million people. The NHS Trust provides specialist care and treatment to people with intellectual disability over four geographical areas, offering a range of specialist interventions and support to meet their health needs. It also offers primary care services through three general practices (GP). The project team consisted of specialist clinicians working with people with intellectual disability in primary, secondary and acute care.

Focus group and Delphi group methodologies were used to systematically synthesise feedback from clinicians and clinical experts in the field.

Ethical approval

According to the Health Research Authority algorithm (see www.hra-decisiontools.org.uk/research/) this study was not defined as research needing ethical approval and therefore did not require submission to the Integrated Research Application System (a single system for applying for the permissions and approvals for health and social care/community care research in the UK). The study received an approval from the NHS Trust's research ethics approval process. Clinical experts were invited and provided consent to participate in the development study.

The study consisted of following work phases:

Work phase 1: review of literature to identify factors that contribute the premature mortality and preventable death

To increase understanding on the factors contributing towards avoidable deaths in people with intellectual disability, a review of the existing literature, up to year 2019, was completed using the databases PsycINFO, CINAHL, EMBASE, ScienceDirect and Google Scholar. A scoping review (Peters *et al.*, 2020) was used to develop and enhance the search strategy. Keywords and their relationships with one another were used for intellectual disability, death, mortality and physical illness. The project followed the guidelines for Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). The studies were critically appraised for quality and relevance using a using the Critical Appraisal Skills Programme (CASP, 2018).

In addition, the project group used the information from a systematic review (O'leary *et al.*, 2018) and from mortality reviews (Heslop *et al.*, 2014; Heslop and Hoghton, 2018) to identify any additional variables that could be considered for the risk stratification tool.

Work phase 2: expert reference group to identify factors that contribute to premature mortality and preventable deaths

The project team conducted five focused groups of multidisciplinary professionals who were directly working with people with intellectual disability and were likely to use the tool in the future. These included psychiatrists; psychologists; health facilitators; general practitioners; speech and language therapists; occupational therapists; physiotherapists; nurses in acute, primary and secondary care; and physicians. An open-ended question method was used with focus group participants to allow for the identification of factors that contributed to avoidable deaths in people with intellectual disability. The feedback from focus groups was thematically analysed and feedback from clinicians transcribed to identify codes and themes (Braun and Clarke, 2006). In addition, as part of routine engagement on intellectual disability services within Cheshire and Wirral Partnership NHS Foundation Trust with service users, their families and carers provided feedback on the barriers faced in accessing health care.

Work phase 3: Delphi groups for consensus statements and weighted scores

The project group combined the information from stage WP1 and WP2 to develop a list of potential factors. The study used Delphi groups made up of clinicians working with people with intellectual disability for identifying suitable factors for a risk stratification tool, and to ensure construct validity of the tool. Delphi group methodology encourages decisions made by a structured group of experts, which are more accurate than an unstructured group or individual opinion (Rowe and Wright, 1999; Trevelyan and Robinson, 2015).

The first Delphi group, consisting of a range of multidisciplinary professionals, synthesised and identified core factors from the list of factors identified through previous work phases. The second Delphi group discussed and agreed on the factors for inclusion in the stratification tool, their weighted scores and the structure of the tool. The following criteria were used to agree on factors to be included in the risk stratification tool: relevance, objectivity of the factor, availability of data, duplication and ease of use in primary care. The group considered the social factors that had an impact on health outcomes. The discussion at the Delphi group highlighted that social factors, or social determinants of health, were not able to objectively stratify risks at a population level but were important impacting factors for everyone with an intellectual disability. It was agreed that the impact of social factors on overall health outcomes varied based on factors such as level of intellectual disability or presence or absence of autism; these factors were included in the final tool. Open-ended questions were used to encourage discussion and support modification of the identified factors. This method allowed for the classification of factors and the formation of the risk stratification tool. For the weighted scores for each item, the group considered the previous literature and data from the national mortality reviews (Heslop *et al.*, 2014; Heslop and Hoghton, 2018).

Work phase 4: piloting the tool in the secondary and primary care

To understand the utility and acceptability of using the tool within the clinical practices, a pilot of the risk stratification tool (Decision Support Tool for Physical Health [DST-PH]) was undertaken. To support the implementation of the pilot, the project team developed guidelines for using the tool and a framework for responding to the level of risks through appropriate interventions.

The first pilot consisted of clinicians from community intellectual disability teams completing the DST-PH with a defined number of patients on their case load and actively receiving interventions from their community team. Team members used information available on the electronic care record system to complete the tool and where sufficient information was not available then additional information was obtained. Clinicians were then asked to complete a feedback questionnaire on clinical utility of the tool with suggestions for any recommended improvements. Collected data was analysed qualitatively for feedback and identified themes and feedback was used to improve the tool.

The second pilot project was completed in the GP practices. Tool was completed by practitioners from three GP practices for patients who were on their intellectual disability register. Clinicians used the available data from their electronic patient record system to complete the tool. Clinicians, including GPs, were asked to provide feedback on the structure and content of the tool, as well as on the clinical utility of the tool. Feedback was further analysed for themes, and suggestions were incorporated to improve the tool and its utility.

Results

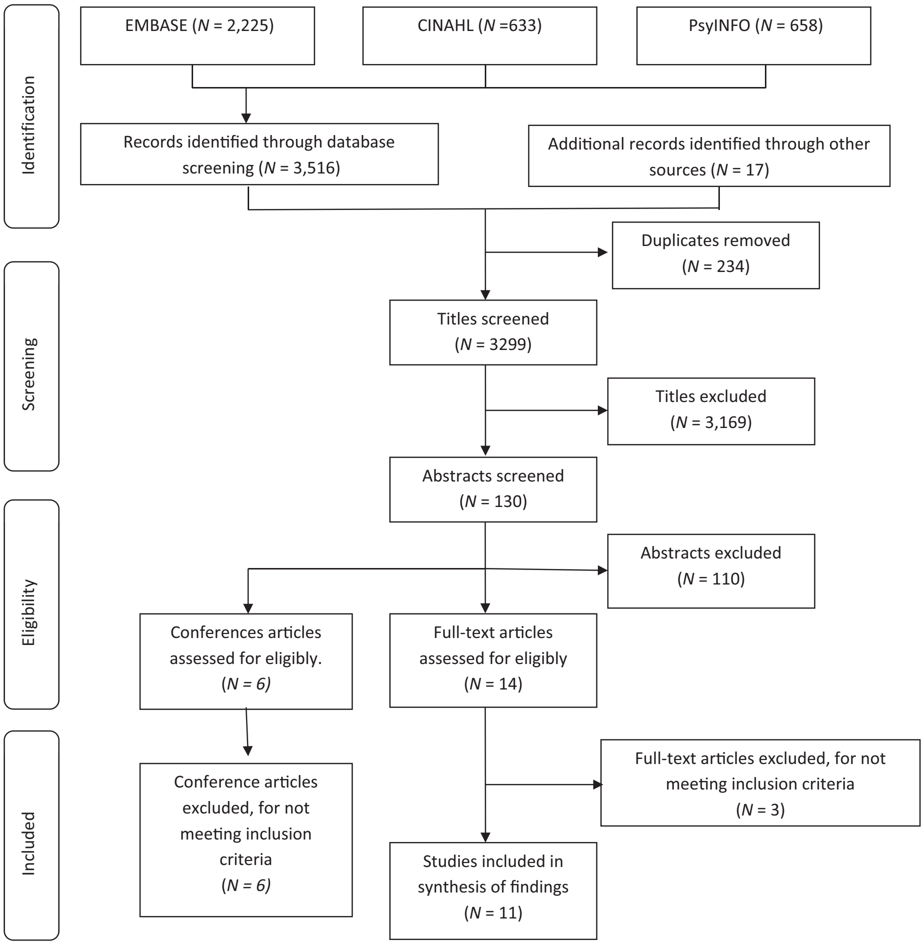
Work phase 1: summary of findings from the review of the literature

The review of the literature explored relationship between clinical and demographic factors and avoidable deaths in people with intellectual disability. It also looked at the studies on the underlying causes for avoidable deaths in people with intellectual disability.

Figure 1 provides the details of the articles assessed, excluded and included at each stage of the process (Moher *et al.*, 2009).

The review identified higher mortality rates for people with intellectual disability compared with the general population (Ng *et al.*, 2017; Trollor *et al.*, 2017). Arvio *et al.* (2017), NHS England (2017) and (2019) and Oppewal *et al.* (2018) reported a link between the severity of intellectual disability and a shorter life expectancy. Studies concluded that the level of intellectual disability was a significant risk factor for premature mortality due to the differences in mortality rates compared with the general population (Arvio *et al.*, 2017; Landes, 2017). Comparisons within studies (Arvio *et al.*, 2017; Brameld *et al.*, 2018; Hunt *et al.*, 2020; Hwang *et al.*, 2019; Landes, 2017; Ng *et al.*, 2017; Trollor *et al.*, 2017) supported findings by LeDeR mortality reviews (Heslop and Hoghton, 2018) and found that people with intellectual disability had a shorter life expectancy than the general population. Additional findings on causes of mortality included respiratory and cardiovascular diseases, epilepsy, dementia and sepsis. The most prevalent causes of death reported for individuals

Figure 1 PRISMA flow diagram



Source: Adapted from Moher, Liberati, Tetzlaff, Altman, & PRISMA Group. (2009)

with intellectual disability continued to be respiratory diseases and circulatory diseases (O’Leary *et al.*, 2018; Heslop and Hoghton, 2018). Table 1 represents the primary causes of death, in order of prevalence, from the studies examined.

Work phase 2: focused groups of clinicians to identify factors contributing to premature mortality in people with intellectual disability

The project team conducted five focused groups of multidisciplinary professionals who were directly working with people with intellectual disability and were likely to use the tool in the future. Details can be found in Table 2. The findings from the literature review were used to further support the development of key overarching variables for inclusion in the stratification tool.

Work phase 3: Delphi groups and the development of the risk stratification tool

First Dephi group identified 29 core factors. These were discussed at the second Delphi group, which identified 19 core factors for the use in the stratification tool. These were divided into two categories, namely, factors that impacted on accessing health services or on the quality of health input received and factors that considered underlying health conditions. Delphi groups

Table 1 Underlying causes of death, in order of prevalence reported for intellectual disability and general population

Underlying cause of death (intellectual disability)	*Underlying cause of death (general population)*	*Study reporting*
Circulatory, neoplasms and nervous disorders	Neoplasms, external causes of death and circulatory	Brameld *et al.* (2018)
"Other", cardiovascular disease and cancer	"Other", cancer and cardiovascular disease	Hunt *et al.* (2020)
Nervous system and sense organ disorders, neoplasm and injury and poisoning	Neoplasms, circulatory, injury and poisoning and nervous system and sense organ disorders	Hwang *et al.* (2019)
Circulatory, respiratory and neoplasms	Not reported	Ng *et al.* (2017)
Respiratory, circulatory, neoplasms and nervous disorders	Not reported	NHS England (2017)
Respiratory, circulatory and congenital malformations/chromosomal abnormalities	Not reported	NHS England(2021)
Respiratory, neoplasms and circulatory	Not reported	Oppewal *et al.* (2018)
Neoplasms, renal and heart conditions	Not reported	Reppermund *et al.* (2019)
Respiratory, circulatory, malignant neoplasms and nervous system disorders	Circulatory, neoplasms and respiratory	Trollor *et al.* (2017)

Source: By authors

also agreed on the appropriate weighted scores for each of these factors. The outcome of these discussions was to have a risk stratification tool (DST-PH) divided into two parts.

Part 1 consists of eight items highlighting factors that could impact physical health outcomes for an individual, including difficulty accessing health-care services. These factors include an individual's level of intellectual disability, being autistic or having other neurodevelopmental conditions, presence or absence of significant behaviours that impacted access to services, presence or absence of an unstable or untreated mental health condition, being prescribed several different types of medications, transition or recent changes in care arrangements, issues with substance misuse and lack of annual health checks and health action plans.

Part 2 consists of 11 items that help identify underlying health conditions or understand a person's physical health needs. The intended purpose of this process is to direct clinicians to ensure appropriate medical treatment and intervention are in place for an individual. Where treatment or medical review is identified as not being actioned, then appropriate interventions can be supported to ensure a more effective review or treatment of physical health needs. This section includes epilepsy, neurological conditions, respiratory difficulties/conditions, cardiovascular conditions, infections, including recurrent infections, cancer/malignancy, posture and mobility-related issues, dysphagia, nutritional problems, gastrointestinal conditions and endocrine conditions.

The scoring of the DST-PH is dependent on the severity of underlying conditions or the impact on an individual's physical health outcomes. The risk stratification tool requires the completion of both parts. The tool uses red, amber and green (RAG) rating based on the overall scores of both parts. The project group used focused groups and case vignettes to identify cut-off points for the RAG rating on both parts. RAG rating of the two parts is combined to get an overall RAG rating, which gives the sense of level of risk (low, medium or high) of avoidable deaths and so that interventions could be tailored accordingly (see Figure 2 for copy of risk stratification tool and scoring matrix [DST-PH]).

Work phase 4: piloting the tool in the primary and secondary care

Qualitative feedback from pilot. The information from the initial pilot in four community intellectual disability services identified several areas of improvement that were required to support the use of the DST-PH tool in clinical practice. Analysis of the feedback from community intellectual disability services identified following issues:

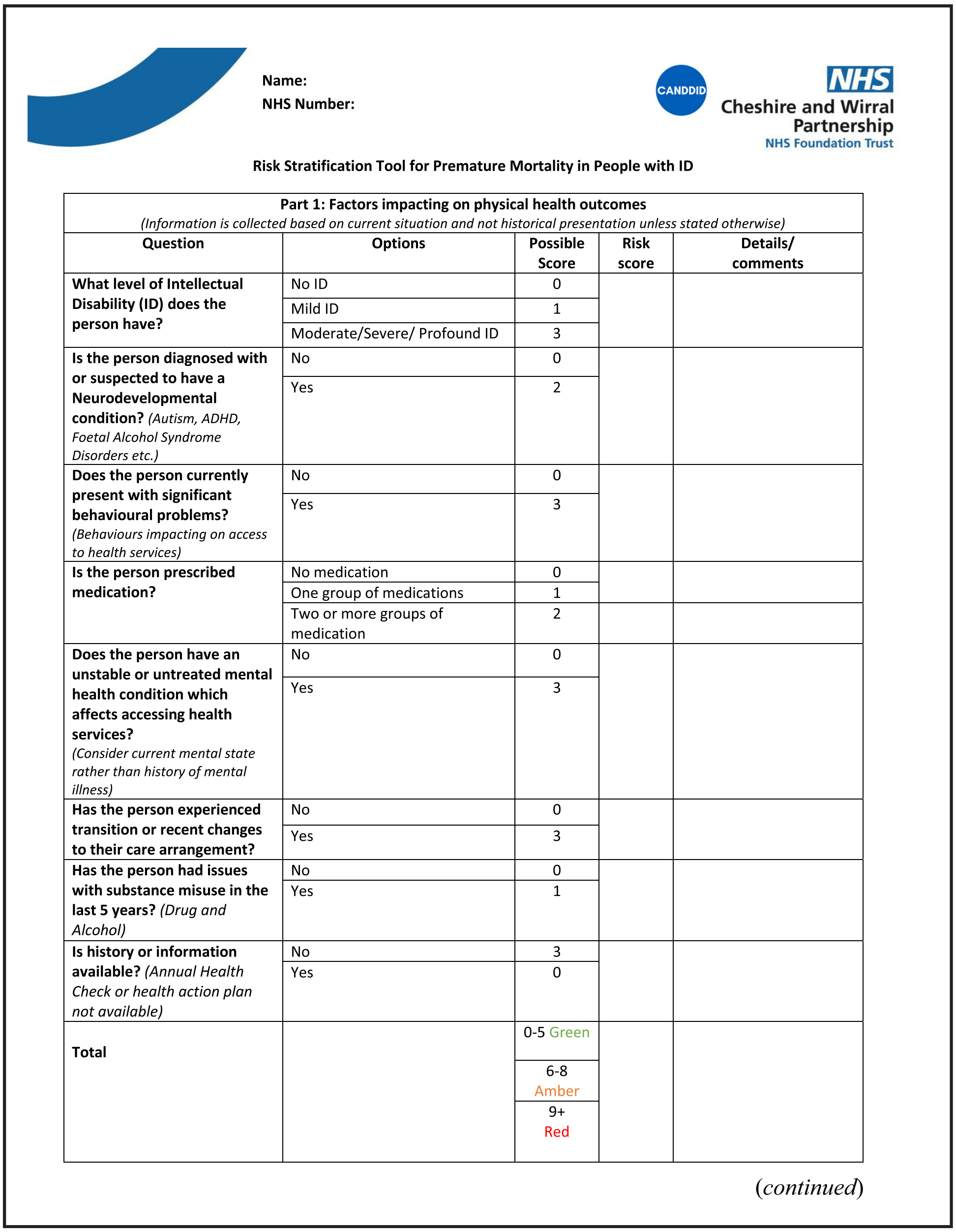
Table 2 Factors contributing to premature mortality and preventable deaths as identified through focused groups

Underlying medical condition	*Other physical health issues*	*Social factors*	*Other person specific factors*	*Process factors*	*Staffing and carers related issues*
Constipation Dysphagia Asthma Respiratory conditions including COPD and bronchopneumonia Osteoporosis Arthritis Obesity or being under weight Neuro-degenerative conditions Dementia Neurological disorders Acquired brain injury Chest infections Skin conditions Congenital heart conditions Epilepsy Deformity/altered body shape Bronchial diseases Diabetes Endocrine conditions Cancer Reflux conditions Abnormal feeding pattern PEG Urinary tract infection Skin integrity Immunological disorders Sepsis Insomnia Pain Immunisation status Aspiration Choking Dehydration Malnutrition History of chest infections Microcephaly Circulatory diseases Congenital malformations Gastrointestinal issues Cardiac failure Genito-urinary conditions Hypertension Hypothyroidism	Mobility Level of activity (inactivity) Sensory impairments Poor bowel management Poor personal care/hygiene Difficulty taking bloods Needing oxygen therapy Hearing Vision Ambulation Level of support needed to eat and use the toilet Gastrostomy feeding Polypharmacy Down's syndrome Syndrome with physical stigmata	Lack of meaningful activities Lack of employment opportunities Social circumstances Family circumstances Family history Poor relationships Low self-confidence Stigma Isolation Lifestyle Lack of support Socioeconomic status Limitations in education Transport difficulties	Level of intellectual disability Age Poor/limited case history Loss of personal history through multiple placements Vulnerability to exploitation Living circumstances Smoking Alcohol/ substance abuse Number of hospital admissions History of medical emergencies Autism spectrum conditions Mental health problems Challenging behaviour Self-harm Psychological factors Risk from others Anti-psychotic medications Long-term use of anti-psychotic medications Communication issues – receptive and expressive Difficulties with engagement Limited capacity	Equipment – amount required and availability Lack of understanding from professionals about the Mental Capacity Act Poor information sharing – with carers, with professionals and with the person Difficulty accessing primary care Difficult accessing secondary care Lack of reasonable adjustments Financial issues Transport problems Lack of accessible communication Discharge without adequate planning Those with continuing health-care funding Lack of annual health checks Post-op (lack of communication and/or reasonable adjustment) Transition from services Poor access to investigations Diagnostic overshadowing Lack of communication between professionals across different organisations Lack of social care Poor access to routine health checks	Care staff not recognising there is a problem in a timely manner Inconsistent staffing Poor recording of information Carers not acting on recommendations Care plans and risk assessments not being up to date Information on different IT systems Changing of staff teams Not using anticipatory care calendar or other health monitoring system Poor carer support

Source: By author

- Double scoring: Same underlying conditions were scored in two or more areas, e.g. infection of respiratory system being scored both under infections and under respiratory conditions.
- Confusion around current health conditions and historical health conditions: Although the tool focused on current health circumstances, the team felt that certain factors were important to rate even when present historically, e.g. history of dysphagia.
- Risk assessment versus risk stratification: Some clinicians struggled to appreciate the concept of risk stratification and relative risk and considered everyone to be of high risk of avoidable deaths.

Figure 2 Risk stratification tool for premature mortality in people with ID



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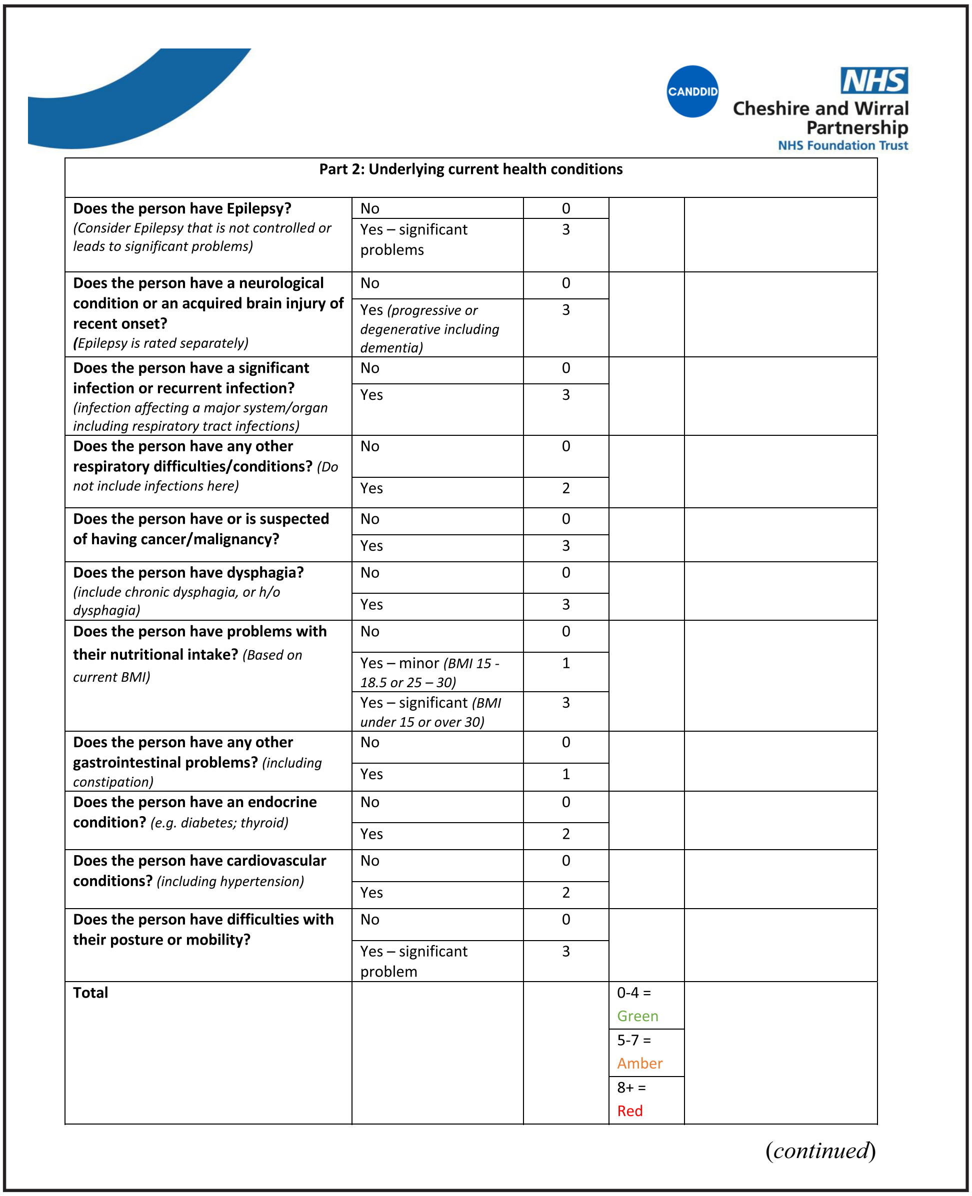
Risk Stratification Tool for Premature Mortality in People with ID

Part 1: Factors impacting on physical health outcomes
(Information is collected based on current situation and not historical presentation unless stated otherwise)

Question	Options	Possible Score	Risk score	Details/ comments
What level of Intellectual Disability (ID) does the person have?	No ID	0		
	Mild ID	1		
	Moderate/Severe/ Profound ID	3		
Is the person diagnosed with or suspected to have a Neurodevelopmental condition? *(Autism, ADHD, Foetal Alcohol Syndrome Disorders etc.)*	No	0		
	Yes	2		
Does the person currently present with significant behavioural problems? *(Behaviours impacting on access to health services)*	No	0		
	Yes	3		
Is the person prescribed medication?	No medication	0		
	One group of medications	1		
	Two or more groups of medication	2		
Does the person have an unstable or untreated mental health condition which affects accessing health services? *(Consider current mental state rather than history of mental illness)*	No	0		
	Yes	3		
Has the person experienced transition or recent changes to their care arrangement?	No	0		
	Yes	3		
Has the person had issues with substance misuse in the last 5 years? *(Drug and Alcohol)*	No	0		
	Yes	1		
Is history or information available? *(Annual Health Check or health action plan not available)*	No	3		
	Yes	0		
Total		0-5 Green		
		6-8 Amber		
		9+ Red		

(*continued*)

Figure 2



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Part 2: Underlying current health conditions

Does the person have Epilepsy? *(Consider Epilepsy that is not controlled or leads to significant problems)*	No	0		
	Yes – significant problems	3		
Does the person have a neurological condition or an acquired brain injury of recent onset? **(***Epilepsy is rated separately)*	No	0		
	Yes *(progressive or degenerative including dementia)*	3		
Does the person have a significant infection or recurrent infection? *(infection affecting a major system/organ including respiratory tract infections)*	No	0		
	Yes	3		
Does the person have any other respiratory difficulties/conditions? *(Do not include infections here)*	No	0		
	Yes	2		
Does the person have or is suspected of having cancer/malignancy?	No	0		
	Yes	3		
Does the person have dysphagia? *(include chronic dysphagia, or h/o dysphagia)*	No	0		
	Yes	3		
Does the person have problems with their nutritional intake? *(Based on current BMI)*	No	0		
	Yes – minor *(BMI 15 - 18.5 or 25 – 30)*	1		
	Yes – significant *(BMI under 15 or over 30)*	3		
Does the person have any other gastrointestinal problems? *(including constipation)*	No	0		
	Yes	1		
Does the person have an endocrine condition? *(e.g. diabetes; thyroid)*	No	0		
	Yes	2		
Does the person have cardiovascular conditions? *(including hypertension)*	No	0		
	Yes	2		
Does the person have difficulties with their posture or mobility?	No	0		
	Yes – significant problem	3		
Total			0-4 = Green	
			5-7 = Amber	
			8+ = Red	

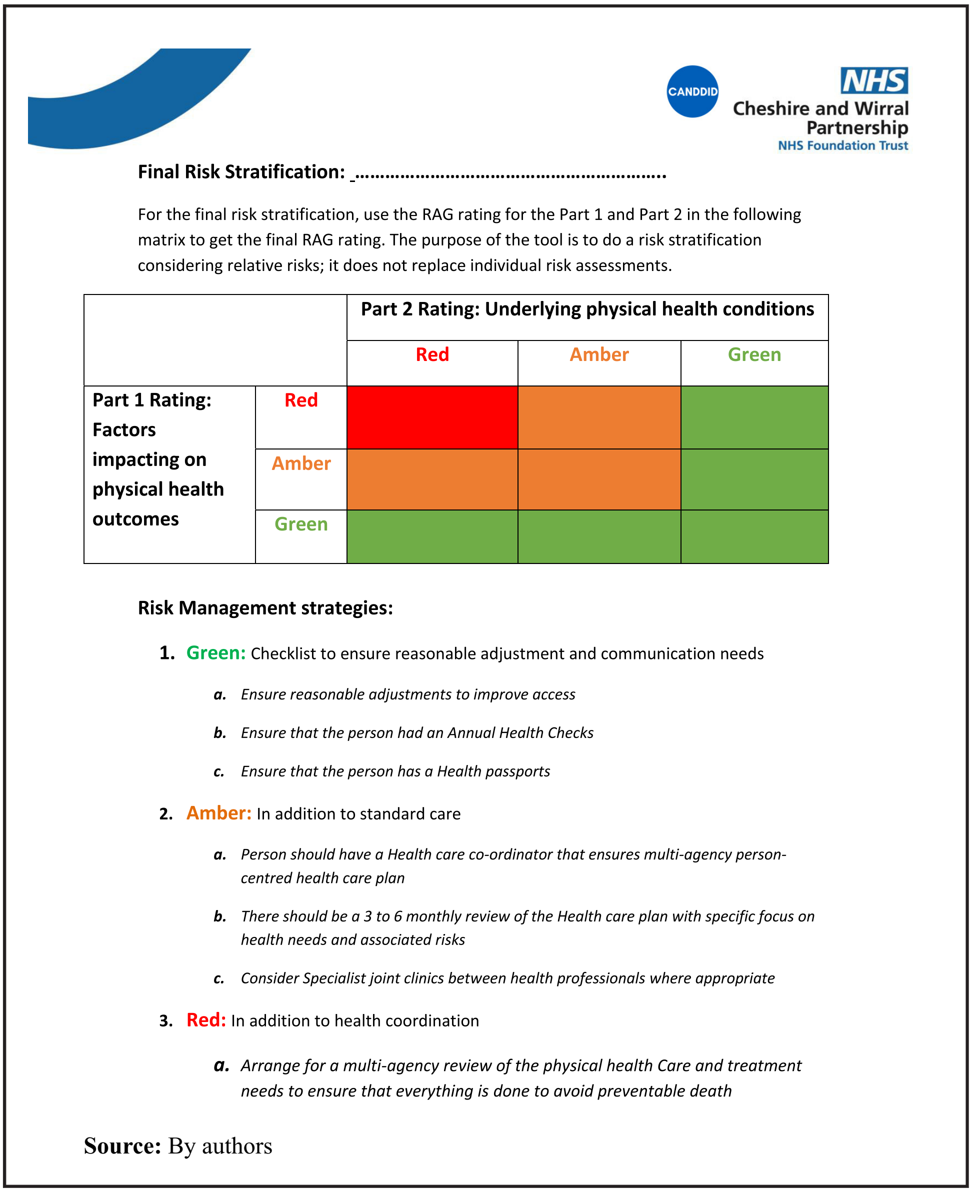
(*continued*)

- Understanding meaning of certain factors: Not everyone had background in physical health and there was some struggle in understanding where certain diseases could be scored.
- Meaning of RAG rating and its implication for clinical practice: Some participants in the pilot needed clarification on the clinical definitions of RAG ratings and services' response based on RAG rating.

To address these issues, the project group made changes to the order and wording of some of the factors within the DST-PH. Clinical guidelines were further revised to support clinicians to use the DST-PH more effectively.

Following subsequent changes to the tool, it was piloted in three GP surgeries. Feedback was very positive. It was felt that the tool was easy to complete and was useful to inform

Figure 2



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Final Risk Stratification: _…………………………………………………….

For the final risk stratification, use the RAG rating for the Part 1 and Part 2 in the following matrix to get the final RAG rating. The purpose of the tool is to do a risk stratification considering relative risks; it does not replace individual risk assessments.

		Part 2 Rating: Underlying physical health conditions		
		Red	**Amber**	**Green**
Part 1 Rating: Factors impacting on physical health outcomes	**Red**	🟥	🟧	🟩
	Amber	🟧	🟧	🟩
	Green	🟩	🟩	🟩

Risk Management strategies:

1. **Green:** Checklist to ensure reasonable adjustment and communication needs
   - **a.** *Ensure reasonable adjustments to improve access*
   - **b.** *Ensure that the person had an Annual Health Checks*
   - **c.** *Ensure that the person has a Health passports*
2. **Amber:** In addition to standard care
   - **a.** *Person should have a Health care co-ordinator that ensures multi-agency person-centred health care plan*
   - **b.** *There should be a 3 to 6 monthly review of the Health care plan with specific focus on health needs and associated risks*
   - **c.** *Consider Specialist joint clinics between health professionals where appropriate*
3. **Red:** In addition to health coordination
   - **a.** *Arrange for a multi-agency review of the physical health Care and treatment needs to ensure that everything is done to avoid preventable death*

Source: By authors

next steps. This pilot suggested minor changes to the wordings of some of the factors and these were acted upon. Figure 2 gives the final tool.

To enhance the implementation of the DST-PH in clinical practice, a framework was developed to direct clinical interventions in accordance with the level of risk for avoidable deaths. These included strategies like health facilitation to improve access to annual health checks, health-care coordination, health care and treatment reviews, etc. Details of these could be found at www.canddid.nhs.uk/DST-PH).

To further support clinical implementation and based on feedback from the pilot project, a training programme was developed using real-life case examples to improve the utility of the tool in clinical practice. A digital media training package was developed and is available and used to support other NHS organisation implement the DST-PH within clinical services nationally.

Discussion

This is the first project in the UK to use population health management principles to develop a risk stratification tool to identify people with intellectual disability who are at higher risk of avoidable deaths. People with intellectual disability form a heterogeneous group of people with wide-ranging needs. Using stratification-based approaches to meet their diverse needs is essential. Using the stratification-based approach, the DST-PH tool could help services identify appropriate strategies at the health and social care system level to reduce the risks of avoidable deaths. Evidence from the literature suggests that only focusing on physical health does not fully address the fundamental barriers for people with intellectual disability (Heslop *et al.*, 2014; Heslop and Hoghton, 2018). The tool considers all the relevant circumstances, including mental health, that would have an impact on overall health outcomes.

The systematic development of the tool ensured face and construct validity. By triangulating information from the available literature and from focus groups, it enabled the development of the tool to have face and construct validity. It also allowed the development of supporting material and an associated response framework. Although the DST-PH was developed locally, by piloting it across four community learning disability teams and three GP practices, the team ensured that the tool could be used across primary and secondary care services.

The key findings of the project were aligned with the results from the review of literature. The findings identified that the level of intellectual disability, diagnostic overshadowing and barriers to accessing health care contribute to poor health outcomes. LeDeR reports have highlighted systemic issues and some examples of good practice (Heslop *et al.*, 2021). However, these good practice examples have mainly focused on specific conditions rather than on solutions at a population level (NHS England, 2017; 2018). The DST-PH, by proactively identifying and providing a systemic framework for response, tries to address these underlying systemic issues that contribute to avoidable deaths. By dividing the tool into two parts, it gives weight to factors that impact health outcomes, e.g. unstable mental health or behaviours that challenge, and to underlying health conditions.

The project developed clinical guidelines and a framework for clinicians to help address known areas of risk such as lack of effective care coordination, poor access and barriers to health-care services. The framework is designed to be an iterative process and, as such, will require continual evaluation to improve clinical responses to those people rated at higher risk of avoidable deaths.

Risk stratification helps to develop strategies to improve health outcomes and reduce health inequalities in a population group. DST-PH provides a risk stratification-based approach for avoidable deaths in people with intellectual disability. The DST-PH could be used in primary and secondary health-care services; it could be used in primary care in conjunction with individuals' annual health checks. This would allow general practitioners to ensure the quality of annual health checks and have a framework for responding to health-care needs in partnership with community intellectual disability services. It could be used at the population level to understand needs and inform population health management strategies.

There are some strengths to this study. Firstly, the development of the DST-PH was a systematic process with multidisciplinary and multi-agency input. The project used information from the published literature and triangulated it with input from professionals and from those with lived experience. It considered both systemic issues and health issues and provided a framework for solutions. Using the pilots for qualitative feedback ensured incremental improvement in the tool, with a resultant increase in its clinical utility and acceptability across primary and secondary health-care services. Since the development of the tool, the COVID-19 pandemic has further highlighted the vulnerability of this population to avoidable deaths. DST-PH could help stratify the population based on risks in future similar pandemics and allow the development of bespoke strategies.

Although the DST-PH provides a framework for the development of systemic solutions to allow clinical services to provide a targeted response for those people identified as at higher risk of avoidable deaths, the tool and the associated response framework require further evaluation. The evaluation of concurrent and predictive validity was beyond the scope of this project and is currently undergoing investigation. In addition, the clinical models to address risks for avoidable deaths would need further development and evaluation in clinical practice, with a focus on medium- and long-term outcomes. Although the tool comes with a suggested response framework from health services, this would need further inquiry and development. The response framework is likely to differ based on the local and regional resources, pathways and where the tool was used (primary or secondary care).

Since the development of the tool, the LeDeR inquiry has highlighted the health inequalities gap for those from black and minority ethnic minority communities. This would need consideration in any future revisions of the tool. The tool has the potential to facilitate the development of strategies to proactively target interventions at the greatest risk. The associated model would have the potential to address issues raised by LeDeR reviews (Heslop and Hoghton, 2018). However, this would need further research and testing at the primary care and regional levels.

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