University of Hertfordshire UH

A pilot evaluation of a novel tool to assess risk of frailty in people living with a learning disability

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Summary

Background: Individuals with learning disabilities may be affected by frailty earlier than the general population. Therefore, there is a need for risk to be identified as early as possible so that appropriate support can be implemented. The overall aim of this study was to carry out a pilot evaluation of the reliability and validity of a novel tool for assessing risk of frailty in people with learning disabilities and gather feedback on its use to inform next steps.

Methods: The Frailty + LD risk assessment tool was used for conducting frailty risk assessments with 52 people in Phase 1a and 110 people in Phase 1b. Individuals were over the age of 18 with a learning disability and were receiving support from the Hertfordshire County Council Adult Disability Service. In Phase 1b, 25 people were assessed twice by two different practitioners to determine inter-rater reliability. Interviews/focus groups were carried out with one person drawing on services, one carer and four practitioners who conducted assessments to obtain feedback on the use of the tool.

Results: It was found that 14% of the overall scores in both phases were incorrect according to the criteria, therefore the corrected scores were used in analysis. In Phase 1a, frailty risk was 46% low, 29% medium and 25% high, and in Phase 1b it was 39% low, 35% medium and 26% high. The tool was used by staff from eight different occupations and took an average of 20 minutes to complete in Phase 1a and 15 minutes in Phase 1b. Using the tool caused practitioners to report changing their opinion of risk in 15% of cases for Phase 1a and 5% for 1b. In 72% of cases in Phase 1b, the practitioners' prior opinion of frailty risk aligned with the outcome of the tool, and in 26% of cases, the frailty risk according to the tool was higher than the practitioner's estimate. For 93% of assessments in Phase 1b, the practitioners agreed with the outcome of the tool. Even, accounting for errors in scoring by practitioners, agreement with the tool is at least 79%, which is considered high. Assessment of inter-rater reliability (agreement between different assessors) found the agreement to be relatively low in Phase 1b (Kappa = 0.26). Qualitatively, the person drawing on services, carer and all practitioners commented on their increased awareness around frailty as a phenomenon because of the tool. Although practitioners felt that the risk assessment could be useful, it did not appear to result in reported changes to people's care or referrals to additional services or pathways in this data.

Conclusion: The Frail + LD risk assessment was used across Hertfordshire County Council with 162 people drawing on services, by practitioners from varying professions. The tool took a relatively short amount of time to complete. The validity and reliability of the tool was assessed in several ways. Between 79% and 93% of practitioners agreed with the outcome of the tool in Phase 1b, providing good evidence for validity of the tool. Although there were differences in opinions in how the tool could be used in future, generally practitioners, along with the individual and carer, felt there was a place for the tool and it was beneficial in raising awareness of frailty. Further investigation and modifications are needed to specifically address the low agreement between different assessors and scoring errors. Any further evaluation would benefit from an extended time period to enable follow-up of outcomes, and to facilitate recruitment and data collection to qualitatively explore stakeholders' views of the tool in more detail. This evaluation demonstrates that the LD+ Frailty tool can be successfully used in practice, identifying people using services who may need more focused evaluation and support.

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Background

Frailty is “a medical syndrome ... characterised by diminished strength, endurance, and reduced physiologic function that increases an individual’s vulnerability for developing increased dependency [*persons with 1 or more deficits in basic activities of daily living]* and/or death.”, as defined by a consensus statement in 2013 (Morley et al, 2013). Whilst this definition focuses primarily on physiological vulnerabilities, theories of frailty recognise its impact across multiple domains, including biological, social, psychological, and environmental vulnerabilities (Fried et al., 2001 Rockwood et al., 2005).

Mencap define learning disability as “a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life” and estimate that it affects 1.5million people in the UK (Mencap, 2023). Although, it is widely agreed that frailty is age-related decline (Martin, McKenzie & Ouellette-Kuntz, 2018; Ouellette-Kuntz, Martin & McKenzie et al., 2015; WHO, 2016), the literature suggests that frailty affects individuals with a learning disability on average 20-30 years earlier than expected in the general population (Ouellette-Kuntz, Martin & McKenzie, 2018; Schoufour et al., 2014). This early decline could be explained by individuals with a learning disability being at greater risk of multimorbidity (McCarron et al., 2013) than those in the general population, and therefore at potentially greater risk of physical decline.

Undetected frailty may increase its progression more rapidly and result in adverse outcomes such as reduction in ability to carry out activities of daily living (ADLs), greater risk of falls, admission to long-term care and early mortality (Jones, Song, Mitnitski & Rockwood, 2005; McKenzie, Martin & Ouellette-Kuntz, 2016). In 2021, individuals with a learning disability in the UK had a mean age of 61 years at death, around 20 years less than the general population (LeDeR report, 2021). Routine frailty assessments do not typically start until the age of 65 (NHS England, 2023) therefore, given the mean age of death and earlier onset of frailty, there is a risk of delayed identification of frailty at more advanced stages in this population. Earlier identification can aid intervention, for example exercise can potentially reverse risk of frailty if detected early (Kenny et al., 2010; Liu & Fielding, 2011; Theou et al., 2011).

Existing tools to identify frailty include the Frailty Phenotype (Fried et al., 2001) and the Clinical Frailty Scale (CFS; Rockwood et al., 2005), however these often do not meet the needs of people living with learning disabilities, as they are more likely to experience multi-morbidity (Kinnear et al., 2018), polypharmacy (O'Dwyer, Peklar, McCallion, McCarron & Henman, 2016), and require support with ADLs (Lante, Reece & Walkley, 2010) compared to the general population. Therefore, individuals with a learning disability may be incorrectly categorised as having a much higher risk of frailty using current assessment tools. This was highlighted as a significant issue during the Covid-19 pandemic as frailty measures were initially used in aiding treatment decisions for patients testing positive for Covid-19, and so those with a learning disability may have been denied lifesaving treatment due to being incorrectly categorised as frail (Tuffrey-Wijne, 2020). In March 2020 it was announced that the CFS is not a suitable method to measure frailty in people with learning disabilities (NICE, 2020), highlighting the need for a novel tool that is appropriate for this population. The aim of this pilot study is to assess risk of frailty using the newly developed Frail + Learning Disability Risk Assessment tool for individuals over the age of 18 with a learning disability.

The Frail + Learning Disability Risk Assessment Tool

The risk assessment tool was developed over approximately 8 months by Adefunke EriOlu at Hertfordshire County Council (HCC) and in consultation with colleagues from HCC, Hertfordshire and West Essex Integrated Care System and Hertfordshire Partnership Foundation Trust in response to an acknowledged gap for people with learning disabilities. It has been designed to identify risk of frailty through consideration of eight domains (see Appendix A), each with three levels of indicators for low, medium, and high risk (initially termed mild, moderate, and severe and changed following Phase 1a). The domains were discussed and agreed by a Health Improvement and Prevention multidisciplinary team.

The individual is categorised for each domain depending on which description best fits their lifestyle at the time of the assessment. The individual is then categorised overall by the following criteria: low if four or more domains are scored as low; medium if three or more domains are scored as medium; and high if two or more domains are scored as high. The overall categorisation determines recommendations for further support e.g., level of management, frequency of health checks and any further action to reduce the likelihood of rapid physical decline.

Phase 1a

Aims

The overall aim of Phase 1a was to demonstrate that the newly developed risk assessment tool is robust in practice and can be successfully used to assess risk of frailty in people with a learning disability.

The objectives of Phase 1a were to:

1) Provide an indication of the clinical utility of the scale in terms of its accuracy in identifying risk of frailty in the target group (sensitivity, specificity, accuracy).
2) Provide an indication of the thresholds for identification of risk of frailty against clinical judgement.
3) Provide feedback from a group of health and care practitioners about how the tool works in practice, and provide indications about how any associated materials, training, and the tool itself needs to be modified.

Methods

Design

Phase 1a was a mixed methods study involving quantitative frailty risk assessments of people drawing on services, as well as a focus group with health and care practitioners once the assessment phase was complete.

Participants

Participants were people receiving support from HCC within the Welwyn and Hatfield Adult Disability Service (ADS). Participants were obtained through health and care practitioners, by conducting assessments with the people they were already working with. Participants were at least

18 years of age and had a diagnosed learning disability. The target number of participants for Phase 1a was 50 assessments, and 52 assessments were completed.

People who had been assessed and support staff/family carers were also invited to take part in interviews/focus groups to discuss their views about the tool. Health and care professionals were also invited to take part in an interview/focus group to share their experiences. No people who draw on services or support staff/family carers took part in the qualitative stage, and two health and care practitioners took part.

Procedure

Health and care practitioners working within the ADS at HCC were provided training on the tool on two occasions. There were two training sessions due to the time period between the first session and the planned start of data collection, therefore the second session was held as a refresher. These were online meetings via Microsoft Teams, run by the project manager and programme lead. These training sessions highlighted the importance of early detection of frailty and aimed to familiarise practitioners with the tool so that they were competent to conduct assessments. Continuous support was also available to practitioners via Microsoft Teams channels.

Following training, practitioners were advised not to select people, and to assess everyone with a learning disability that they were working with. People were informed of the purpose of the assessment and asked to provide consent, which was the responsibility of HCC. Where the person lacked capacity to consent to participate in the study, a best interest decision was made. People were present while practitioners conducted the assessment, and support staff or family carers were also present if required. Assessments were conducted at the individual's place of residence at the time of assessment, which may have been a residential home, supported living, or their own home. Practitioners had a paper copy of the assessment tool which they used for scoring.

Once the assessment was complete, practitioners then accessed an online Smart Survey where they could input the data. This survey contained additional questions to gather demographic information (age, gender, accommodation status and ethnicity) as well as the length of time the assessment took and whether their opinion of frailty risk had changed following the assessment. For certain questions on the survey, practitioners were able to provide open text comments, for example for "Has your opinion of frailty risk changed following the assessment?" there was an optional open text box to elaborate on their answer. During the assessment, the practitioners asked people who they felt would have capacity to consent and support staff/family carers if they were interested to find out more about taking part in an interview or focus group to discuss their experiences of the tool.

A total of three health and care practitioners who had conducted at least two assessments were emailed by the HCC project manager and asked if they'd like to participate in a focus group as an opportunity to provide their feedback of the tool. Those who were interested responded to the research team via email. The University of Hertfordshire (UH) team liaised with the practitioners to set a date and time for the focus group. They were sent an electronic participant information sheet (see Appendix B) and consent form (see Appendix C), which was to be electronically signed and sent back before the focus group. The focus group consisted of two practitioners, was conducted online via Zoom and lasted approximately 60 minutes in length. One participant had technical issues throughout and as a result was not there for the whole focus group. A topic guide was used (see Appendix D) and involved questions around the training of the tool and any improvements, how practitioners found using the tool in practice, any issues or difficulties, and any improvements or considerations for the future of the tool.

Data analysis

The data from the online survey was anonymised and made available for staff (DG) at UH to access via Herts FX, a web-based application that allows HCC staff to exchange files securely with third parties over the internet. The data was analysed descriptively. Any comments that practitioners provided in the survey were not analysed systematically as there was only a limited number provided, but where relevant they have been included in the report for context and additional interpretation.

The focus group was audio recorded and transcribed. The intention was to use reflexive thematic analysis using NVivo software to draw commonalities and potential tensions across accounts but due to the lower number of participants than anticipated, the analysis plan was adapted. The transcription was read by two analysts (who conducted the focus group) who independently made reflective notes on key points highlighted by the participants around their experiences using the tool and any issues or improvements that could be made to the tool and its implementation for the next phase of the study. The analysts discussed their reflections, and these were synthesised into key themes for the report, with quotes to illustrate their findings.

Ethics

Ethical approval was gained from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Subcommittee (Protocol number: LMS/SF/UH/04841). All health and care practitioners who participated in the focus group were provided a participant information sheet outlining the purpose of the study. They were also explained the purpose and procedure of the focus group verbally by a researcher at the beginning of the focus group. Health and care practitioners gave their informed consent to participate by signing the form electronically, as well as verbal consent at the start of the focus group which was audio recorded. Anonymity was maintained for both the assessment data and the focus group data using participant ID codes.

Results

Frailty risk assessments

<u>Sample characteristics</u>

A total of 52 people were assessed using the tool between 28th March 2022 and 13th June 2022. Their demographic details can be found in Table 1. The average age of people who received an assessment was 52 years *(SD = 13.6)* with ages ranging from 25 years to 76 years. Just over half of the people lived in a residential setting (51%) and all 52 were White. It was not recorded how many people required a best interest decision, i.e., lacked capacity to consent.

<u>Assessment time</u>

The time taken to complete assessments for health and care practitioners ranged from 5 to 30 minutes, with 20 minutes being the most frequent time for the 36 assessments where time was recorded (see Figure 1). Figure 2 shows that health and care practitioners became considerably quicker at completing assessments as time went on, taking an average of 20 minutes for assessments 1-10 and halving this to an average of 10 minutes for assessments 40-50.

Table 1: *Demographics profile of the 52 people assessed using the tool.*

Demographic	
Gender they identify as: n (%)	
Male	30 (58)
Female	22 (42)
Age (years): M *(SD)*	52.2 (*13.6*)
Accommodation status: n (%)	
Living with family	9 (17.3)
Supported living	17 (32.7)
Residential	27 (51.0)
Ethnicity: n (%)	
White - English/Welsh/Scottish/Northern Irish/British	51 (98.0)
White – Irish	1 (2.0)

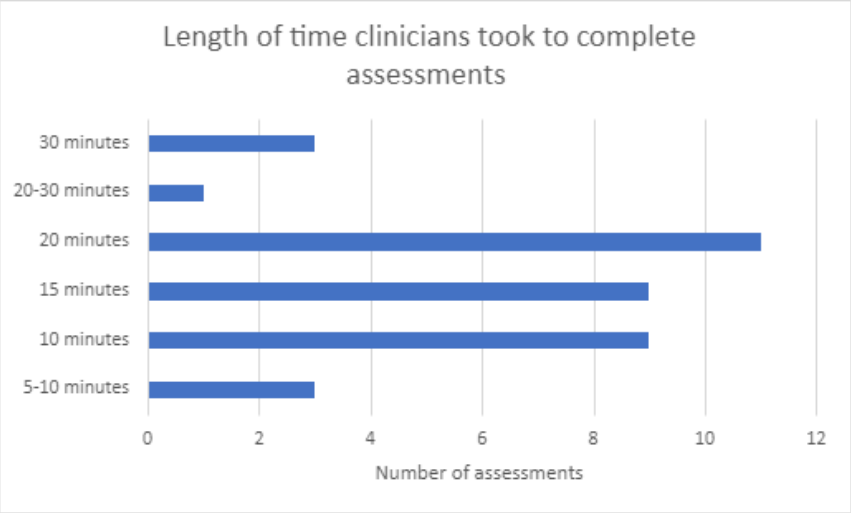

Figure 1: *The length of time health and care practitioners took to complete assessments in minutes.*

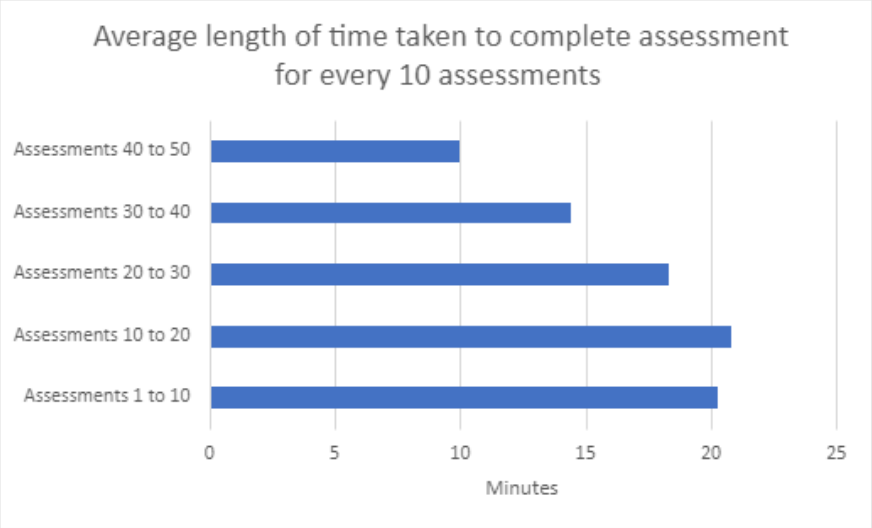

Figure 2: *The average length of time taken to complete an assessment for each group of 10 assessments.*

Checking the scoring of assessments

Each assessment was reviewed to check whether the overall risk was correct based on the scoring criteria. All 52 assessments were checked, and one was found to be incorrect. In this case the practitioner had categorised the individual as mild risk when they should have been moderate risk. The following analyses have been conducted with this corrected score.

Risk of frailty

In terms of overall frailty risk, 23 out of 52 (44%) people assessed were categorised as mild risk, 16 out of 52 (31%) as moderate and 13 out of 52 as severe risk (25%) (see Figure 3).

Figure 4 shows the frequency of scores for each of the eight domains. Domain 5 (Support) and domain 3 (Insight) were the two domains that had the highest level of severe ratings. Some responses had missing data which explains why there are not 52 responses for all eight domains. Overall, the distribution of scores demonstrates that the scale works well, with little evidence of a ceiling (or floor) effect.

Health and care practitioner opinion of risk

In 8 out of 52 assessments, completing the tool led practitioners to change their clinical opinion as to whether the individual was at risk of becoming frail over the next year. At 15% of assessments, this is a significant proportion. It is unclear from the data which direction these changes occur (e.g., whether the change was mild to moderate or vice versa). Nonetheless that approximately 15% of assessments led to a change in the assessed level of risk indicates that services may have an inaccurate understanding of the level of risk of people drawing on services, which could have implications for redirecting resource allocations.

Focus group with health and care practitioners

Three health and care practitioners accepted the invitation to participate in the focus group, however one was unable to attend due to sickness therefore two participated. Topics of significance that were raised in the focus group have been discussed below. Due to technical issues, one participant did not contribute as much to the focus group and therefore there are fewer quotes from them.

Training to use the tool

One participant stated that the training was very good and appreciated being able to speak to the project team following training.. It was highlighted that perhaps a bit more support was needed in addition to the two training sessions, and that it may have helped if the training was closer to starting the assessments. One health and care practitioner had a preference of the training being conducted in person and felt that having paper copies of the materials during would have been helpful.

> *HCP 2639 - "I think they did really well when doing the training"*
>
> *HCP 2639 - "I think if it was face to face and all the hard copies are there and people, when you're talking about them can actually pick up the assessment and look through or pick up the survey and look through, I think that would probably, I think that would probably clarify a lot better what's expected."*

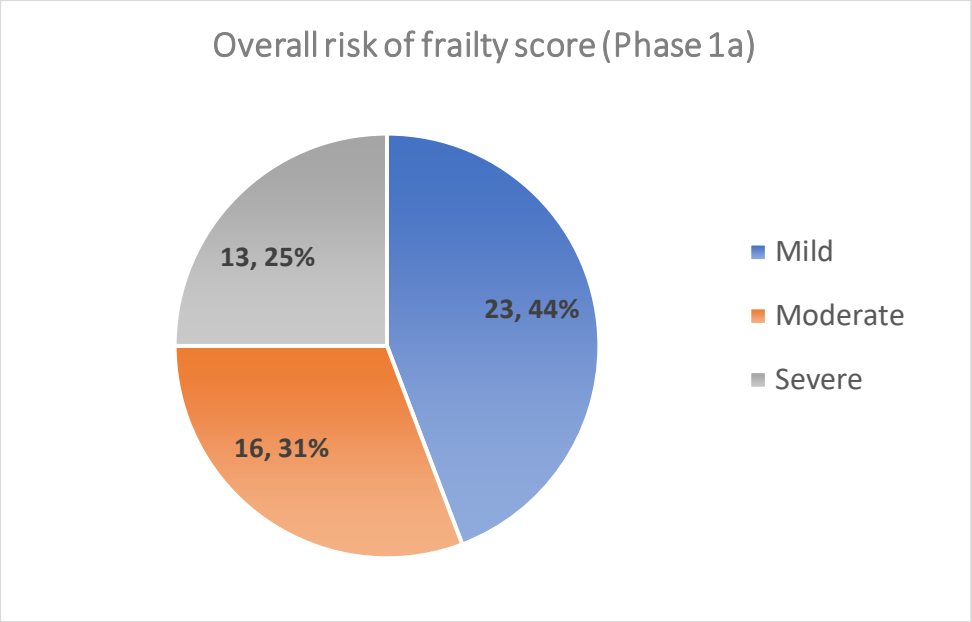

Figure 3: *The proportions of mild, moderate, and severe frailty risk for 52 people assessed.*

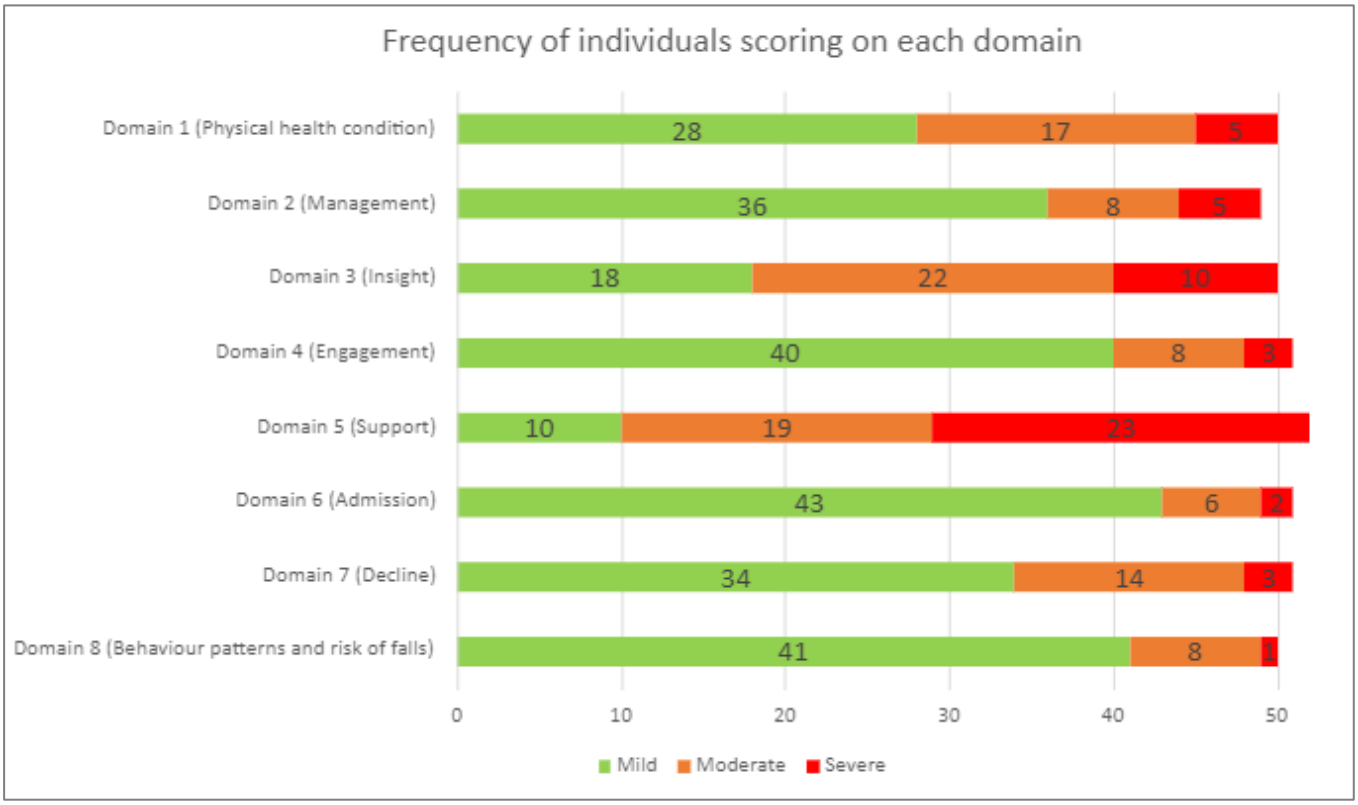

Figure 4: *Frequency of scores on each frailty risk domain.*

Awareness of frailty

Health and care practitioners mentioned that the GPs only do frailty assessments for people over 65 years of age, and that frailty is not normally assessed unless the individual had a fall. One participant highlighted that people with learning disabilities may not even reach the age when a frailty assessment is conducted and therefore it is important to investigate it, suggesting how it may be incorporated into routine practice.

> *HCP 5634 - "I think it's really good, and it may be, you know, should be part of the annual health check"*

Both participants stated that using the tool to conduct assessments had increased their awareness around people on their caseload who could potentially be at risk of becoming frail, particularly younger people who draw on services who they may have assumed to not be at risk of frailty because of their age.

> *HCP 2639 - "I suppose it is that stereotypical whenever you think of someone being frail you think of an old person, and I suppose that was in my mind, and I think this obviously highlighted, um to the point, that obviously young people could be frail"*

Uncertainty around domain 5 (support)

Both participants stated that people assessed often categorised as severe for the support domain as many of them were receiving 24-hour support.

> *HCP 5634 - "That was, making it very making the, making it very high all the time you know the outcome"*

Due to this domain often being categorised as severe, health and care practitioners were sceptical about the overall outcome as it appeared to be inconsistent with what would have been their clinical judgement.

> *HCP 5634: "This guy [individual who was assessed] goes to garden centres every day and is out walking about every day, but because he lives in 24/7 settings that pushed him over that threshold"*

Collaborating with support staff and carers

Both health and care practitioners mentioned needing support from carers or support workers to help complete assessments of people they were not familiar with, otherwise it would have been difficult to complete. This highlighted the importance of collaborating with support staff when conducting assessments and ensuring the language of the tool was appropriate for people who may not be as familiar with the concept of frailty.

> *HCP 2639 – "I had to do some that weren't on my caseload that I didn't really know very well so then obviously yeah it was essential that the support staff were on board and obviously they know the person very well."*

Balancing the assessment with existing workload

Participants both agreed that although they enjoyed conducting assessments and felt they could be beneficial, staffing issues at the time meant it was challenging to get assessments completed.

> *HCP 2639 – "We've really enjoyed doing it, but I think it actually came at the wrong time for us."*

Lack of individual's and carer's interest in focus groups

Due to the lack of uptake from people who were assessed and carers in focus groups, practitioners were asked about their experiences talking to people about this stage of the research. They noted that support workers often declined due to being too busy.

> *HCP 2639 - "When we asked them about the support, the focus group, though, but yeah they weren't interested really"*

Regarding people who draw on services, health and care practitioners felt that few would be able to engage in a focus group, either because they felt that they would lack capacity to consent or because they felt it would not be appropriate for their clinical needs.

Conclusions and lessons learnt from Phase 1a

The overall aim of Phase 1a was to conduct a pilot study to explore the use of the newly developed Frail + Learning Disability Risk Assessment tool in practice and gather initial data about whether it can be successfully used to assess risk of frailty in people with a learning disability. Assessments took place with 52 people, surpassing the target of 50. The process of conducting assessments and the focus group were beneficial in identifying areas for improvement in both the tool and its implementation, and a number of changes were identified for Phase 1b.

Regarding overall risk of frailty for the sample, nearly half (44%) were categorised as mild risk. The "support" domain was most frequently scored at the highest risk of frailty, implying that many of the people assessed required regular or constant support. Health and care practitioners in the focus groups highlighted that this indicator was often scored higher than they would expect.

Notably, in 15% of the assessments, practitioners reported a change in their opinion of frailty risk having used the assessment tool. Although a significant proportion, it became clear once data had been collected that it was difficult to ascertain whether the assessors' opinions had changed in terms of being at higher or lower risk of frailty than initially predicted. Nonetheless this presents the risk of a significant level of misallocation of resources to people being looked after by the service. To determine this in Phase 1b, health and care practitioners were asked to rate their opinion on risk of frailty both before and after the assessment so that we were able to determine the direction of their change and provide valuable insight into the validity of the tool.

In order to obtain feedback on the use of the tool, a focus group was conducted. Health and care practitioner input was helpful in identifying several issues with the wording of the tool and supporting documents. It was also acknowledged throughout the focus group that practitioners may have viewed the tool as assessing current frailty rather than risk of frailty in the future. Therefore, for Phase 1b the training, wording of the tool and additional resources placed an emphasis on this being a risk assessment. The categorisations for the eight domains and overall risk of frailty were also changed to from "mild", moderate", "severe" to "low", "medium" and "high" respectively, to further highlight risk rather than current frailty. The focus group did reveal some uncertainty about the outcome of some assessments, specifically where the individual assessed scored higher than the practitioner expected. Emphasising that this is an assessment of risk rather than current frailty may also help reduce doubt in these scenarios.

The time taken to complete assessments decreased over time to an average of 10 minutes in the final group of assessments, which may have been due to practitioners becoming more confident using the tool. However, it was noted that practitioners sometimes felt they did not have time to complete the tool due to staffing levels and the demands of the service. To aid our understanding about how to facilitate this tool being incorporated into routine clinical practice, Normalisation Process Theory (May et al., 2009) was utilised as a framework for the interviews in Phase 1b to aid the identification of potential barriers to implementation.

One of the main challenges faced during this phase of the pilot was the difficulty in engaging people who received an assessment and carers to consider participating in focus groups. According to the practitioners, many people that were assessed did not have capacity and so were not eligible, however those who were eligible were not reported to be interested in participation and carers were reported to decline due to lack of time available. To try and improve participation rates for Phase 1b, initial information sheets were created with the input of experts by experience to provide an accessible one-page summary of what participation would require.

Conclusions

To conclude, in this phase of the pilot study we were able to successfully conduct frailty risk assessments with 52 people with a learning disability. The data indicated that over 50% of those assessed were at moderate (31%) or severe (25%) risk of frailty. It was also found that approximately 15% of assessments led to a change in the assumed risk of frailty, which indicates a significant risk that people using the service may be allocated services inappropriately (approximately 1 in 6), either having too much, or too little focus on their needs.

The scale appeared to work well, with no apparent ceiling (or floor) effect apparent in the response distribution. While there were differences in the distribution of assessed risk across domains, the qualitative data provides some indication of changes to wording or training that may address these differences. Health and care practitioners stated that using the tool to conduct assessments had raised their awareness around factors that could contribute to existence of frailty, as well as the importance of early detection.

Several issues were highlighted in this pilot, including the low recruitment to focus groups, wording of the tool, and referring to the assessment as current frailty rather than risk of frailty. There was therefore a focus on these for Phase 1b.

Phase 1b

Aims

The purpose of Phase 1b was to build on the knowledge obtained from Phase 1a with a larger group of participants in HCC (target of 200 people drawing on services) to further develop evidence of the validity and reliability of the Frailty + LD risk assessment tool and how this was used in practice.

The objectives of Phase 1b were to:

1) Provide an indication of the inter-rater reliability of the scale.
2) Provide an indication of external validity for identification of frailty risk against clinical judgement.
3) Obtain feedback from people who were assessed, carers (either professional or informal) and health and care practitioners regarding use of the tool in practice.

Methods

Design

Phase 1b was a mixed methods study involving quantitative frailty risk assessments of people who draw on services, and two interviews with health and care practitioners, as well as an interview with a person who received an assessment and a family carer once the assessment phase was complete.

Participants

Participants were people who draw on support from HCC within the ADS. Phase 1a covered only the Welwyn and Hatfield area, whereas Phase 1b was extended to also include Broxbourne, Dacorum, East Hertfordshire, St Albans, Stevenage, Three Rivers, Watford, and Hertsmere. It should be noted that none of the people that were participants in Phase 1a were participants for Phase 1b.

Participants were obtained through health and care practitioners of HCC who conducted assessments with people they were already working with. Assessments were conducted at the people' place of residence at the time of assessment, which may have been a residential home, supported living, or their own home. People were at least 18 years of age and had a diagnosed learning disability. The target number of participants for Phase 1b was 200. The final numbers receiving an assessment were 110 people, with 25 of these people receiving two assessments (a total of 135 assessments).

As in Phase 1a, people who were assessed, support workers/family carers and health and care practitioners were invited to take part in interviews/focus groups. Health and care practitioners were invited if they had completed at least one assessment. A total of four participants were recruited for the qualitative stage: two health and care practitioners, one individual who was assessed and one family carer.

Procedure

The procedure for Phase 1b was largely the same as Phase 1a. Training sessions for practitioners from the 10 localities of Hertfordshire were conducted via Microsoft Teams, run by the project manager, project lead, frailty and falls advanced practitioner, and senior community learning disability nurse. As with Phase 1a, continuous support was also available to practitioners via Microsoft Teams channels. Once they had received training, practitioners completed assessments and uploaded their results onto an online Smart Survey. Several additional questions were added to

the survey, including the assessor's occupation, their estimate of frailty risk before the assessment, whether they felt the outcome was an accurate reflection of the individual's frailty risk, and what they thought the frailty risk should be if they did not agree with the outcome. These were added so that additional analyses could be conducted to help draw conclusions. As with Phase 1b, several questions also had space for additional comments.

Another addition to the procedure for Phase 1b was for at least 10% of the people to be assessed twice to investigate inter-rater reliability, which is the extent to which two independent assessors are in agreement. These assessments were to be performed by different practitioners and were to be conducted within approximately one month of each other to minimise the likelihood that any variations were due to improvements or decline in the health of the individual being assessed.

As with Phase 1a, practitioners were asked to share brief information about participating in a focus group or interview with people they felt were likely to have capacity to consent. Carers, which could be family members or professional carers, were also asked if they would be interested. Contact details were collected for those who were interested, and an Excel spreadsheet of all contact details was sent securely from HCC to staff (DG and SM) at UH. Potentially interested people who draw on services and carers were also provided one page information sheets (see Appendices E and F, respectively).

A total of 10 people who draw on services and two carers expressed interest in participating. Researchers at UH then attempted to contact them at least twice, either via email or phone, or both. In many cases, no one answered the phone, and a message was left with a brief introduction including the reason for calling and contact details of researchers if they were interested. In several cases, the contact number provided was for the residential home where the person lived and therefore a member of staff answered the phone and said they would pass on the message to them. Despite best efforts to contact all those who expressed interest, only one person drawing on services and their family carer agreed to participate. We did not receive a response from the remaining people we contacted.

The interview was conducted at the people' home with both them and their family carer involved. Full information sheets and consent forms (see Appendices G, H, I and J) were used and a topic guide was followed for the interview (see Appendix K).

Regarding health and care practitioner interviews, the same procedure was adopted for Phase 1b as with Phase 1a where HCC sent an email to health and care practitioners who had conducted assessments and asked them to contact the research team if they were interested. A total of 26 practitioners were emailed three times regarding the focus groups. They were also sent a one-page information sheet (see Appendix L). Researchers at UH created some dates for focus groups which were offered to practitioners. Only two practitioners volunteered however they had different availability therefore, two separate interviews were conducted on Zoom. The Phase 1a topic guide was updated, drawing on Normalisation Process Theory, and the version used for Phase 1b can be found in Appendix M. The same information sheets and consent forms were used as in Phase 1a (Appendices B and C, respectively).

Due to lack of uptake from health and care practitioners for the focus group, in March 2023, health and care practitioners were given the option of providing email feedback. The email sent can be found in Appendix N and the information sheet can be seen in Appendix O. The UH team wrote the email, and this was sent to a total of 30 health and care practitioners by HCC, with a request to return any feedback via email to the UH team. No responses were received.

Data analysis

The data from the online survey was anonymised and made available for staff (DG) at UH to access via Herts FX. The data was analysed descriptively. Any comments that practitioners provided in the survey were not analysed systematically as there was only a limited number provided, but where relevant they have been included in the report for context and additional interpretation.

Interviews were audio recorded. Zoom produced an automatic transcript for the health and care practitioner interviews. These transcriptions were read by two analysts (who conducted the interviews) who independently made reflective notes on key points highlighted by the participants around their experiences using the tool and any issues or improvements that could be made to the tool and its implementation. For the in-person interview, the analysts listened to the audio recording and made reflective notes. The interview was transcribed using Descript and analysts discussed their reflections, and these were synthesised into key themes for the report, with quotes to illustrate findings.

Ethics

Ethical approval was gained from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Subcommittee (Protocol number: LMS/SF/UH/05128), following the same processes around information and consent as Phase 1a. An amendment was approved by the same ethics committee at the University in March 2023 to reflect also collecting feedback from health and care practitioners via email.

Results

Frailty risk assessments

Data was received from HCC for a total of 137 assessments. One record did not contain any data therefore it was excluded. 25 people were assessed twice to investigate inter-rater reliability, and one individual was assessed three times due to error. Their third assessment data was excluded from the analysis. This left a total of 110 people, with 25 receiving two assessments (a total of 135 assessments).

Sample characteristics

A total of 110 people were assessed using the tool between 1st October 2022 and 15th February 2023. 47% of the assessments were conducted as a best interest decision, indicating the individual did not have capacity to consent. The demographic details for the people who were assessed can be found in Table 2. The average age was 56.3 years *(SD = 14.2)* with ages ranging from 26 years to 87 years. Regarding accommodation status, the most frequently reported was Supported Living, with the next common being Residential. The sample was largely of White ethnicity at 90%. Severity of learning disability varied, with 33% categorised as low, 46% as medium and 21% as high severity.

Health and care practitioner occupation

Regarding occupation of the assessor (see Table 3) nearly two thirds (63%) of the assessments were conducted by learning disability nurses. The second most common occupation was health care assistant at 14%.

Table 2: *Demographics of the 110 people assessed using the tool.*

Demographic details	
Gender they identify as: n (%)	
Female	53 (48)
Male	55 (50)
Prefer not to answer	1 (1)
Blank	1 (1)
Age (years): M *(SD)*	56.3 (*14.2*)
Minimum age	26
Maximum age	87
Accommodation status: *n* (%)	
Living with family	13 (12)
Supported living	45 (41)
Residential	33 (30)
Living independently in own home	4 (7)
Living independently with support in own home	11 (10)
Other	4 (4)
Ethnicity: *n* (%)	
Asian/Asian British	4 (4)
Mixed/Multiple ethnic groups	5 (5)
White British	99 (90)
Other ethnic group	1 (1)
Prefer not to answer	1 (1)
Severity of learning disability: *n* (%)	
Low	36 (33)
Medium	51 (46)
High	23 (21)

Table 3: *Occupation of the assessor for all 135 assessments.*

	Primary Assessment (n=110)	**Repeated Assessments (n=25)**	
Assessor Occupation	**Freq (%)**	**Assessment1 – Freq (%)**	**Assessment2 - Freq (%)**
Community Care Officer	5 (4%)	1 (4%)	-
General Nurse	4 (4%)	-	-
Health Care Assistant	15 (14%)	1 (4%)	-
Learning Disability Nurse	70 (63%)	22 (88%)	1 (4%)
Occupational Therapist	3 (3%)	-	-
Social work apprentice (third year)	1 (1%)	-	-
Social Worker	9 (8%)	-	24 (96%)
Student Learning Disability Nurse	3 (3%)	1 (4%)	-
Total	110	25	25

Assessment time

The time taken to complete assessments for practitioners was recorded for 98 of the 110 assessments, as 11 records had no data for this question. The time taken ranged from 5 to 180 minutes, with most assessments completed in 10 to 20 minutes (75/98, 77%), and 64 (65%) completed in less than 15 minutes (see Figure 5). It is noticeable that a small number of assessments took an hour or more to complete.

Checking the scoring of assessments

The overall frailty risk score for each assessment was reviewed to check whether it was correct based on the scoring criteria. All assessments (both initial and repeated assessments) were checked and a total of 26 assessments out of 135 (19%) were not scored as would be expected based on the criteria.

For 19 of these 26 incorrectly scored assessments, we concluded that the assessor likely gave the most frequent domain score as the overall score, i.e., if the majority of domains were scored as low, then low was also given as the overall score regardless of the number of domains scored as medium or high. For 6 out of the 26 assessments, it was unclear why the assessor chose that category, therefore potentially it was the overall categorisation the assessor felt best described the individual at the time. For one of the assessments, it is unclear why the assessor chose medium as there were 6 domains scored as high, therefore we speculate that this may have been an input error.

The following analyses have been conducted based on the corrected scores.

Risk of frailty according to the tool

In terms of overall frailty risk according to the tool, 43 out of 110 (39%) of people assessed were categorised as low risk, 38 out of 110 (35%) as medium risk and 29 out of 110 (26%) as high risk (see Figure 6).

Assessed risk across domains

Figure 7 shows the frequency of people' scores for each of the eight domains, and Table 3 shows the correlation between the domain score and the overall risk score. Support (domain 5) and Insight (domain 3) had the highest levels of high-risk rating. This is consistent with the findings from Phase 1a. Both Support (domain 5) and Insight (domain 3) show moderate to high correlation with the scale score. While the Management, Physical, Engagement and Decline domains also show reasonable correlation with the scale score, correlations for the Admission and Behaviour domains is below 0.50. Overall, the relationship between a number of domains and the scale score is lower than desirable, although further data would be needed to enable an understanding of why this is the case. It is possible that there are two clusters of domains that relate differently to the overall assessment (Physical, Management, Insight, and Decline, versus Engagement, Support, Admission and Behaviour). A larger data set would be required to assess the underlying relationships between these elements of assessment.

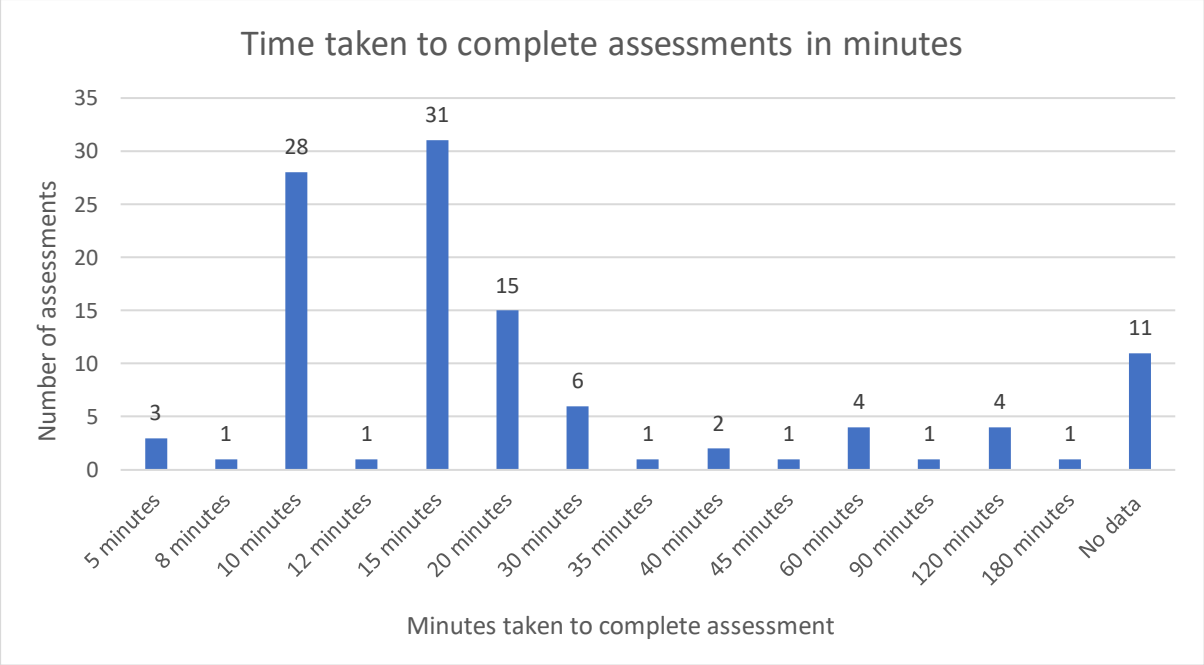

Figure 5: *Time taken to complete assessments for 98 assessments.*

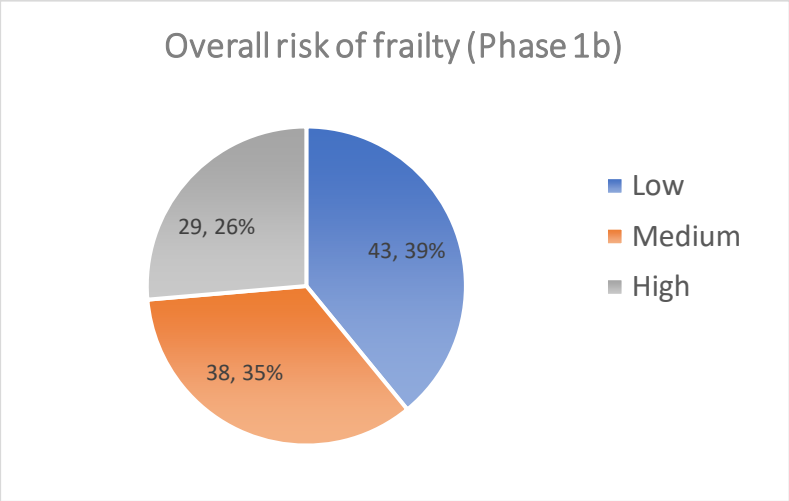

Figure 6: *The proportions of low, medium and high frailty risk assessed for 110 people who were assessed.*

Table 3: *Correlation between domain scores and the scale score*

Domain	1 Physical	2 Management	3 Insight	4 Engagement	5 Support	6 Admission	7 Decline	8 Behaviour
Correlation	0.66	0.68	0.61	0.51	0.60	0.46	0.55	0.48

Note: Pearson's rho. All correlations were significant.

Change in assessed frailty risk

Practitioners were asked to estimate the individual's frailty risk prior to conducting the assessment. Twelve out of 110 (11%) were initially categorised as no risk, 47 out of 110 (43%) as low risk, 37 out of 110 (33%) as medium risk and 14 out of 110 (13%) as high risk. Therefore, over half (54%) were initially considered by assessors to have either no or a low risk of becoming frail.

Figure 8 shows the estimate of frailty risk prior to the assessment and frailty risk according to the outcome of the tool. There was the option to rate "no risk" on the prior estimate question, which is not an outcome on the tool, so this was merged with the low-risk category. Both the assessed risk in the medium and high-risk categories increased, by 2% and 13% respectively. Consequently, the percentage of people categorised as low risk was reduced by 15%. This indicates that the tool generally categorised people as having a higher risk of frailty than the assessors' initial estimate.

Table 4 shows the change in frailty risk before and after the assessment. For 79 (72%) of the 110 assessments the frailty risk score did not change from the assessor's initial estimate. For the remaining 31 (22%) assessments the outcome was different to the assessor's initial opinion (see those with * in Table 4). Of those 31 assessments, 2 resulted in a lower risk rating (both medium to low) and 29 resulted in a higher risk rating, with 14 of these increasing from low to medium, 11 increasing from medium to high and 4 increasing from low to high.

Assessing the validity of the LD+ Frailty tool

To aid assessment of the tool's validity, the health and care practitioners were asked questions about their opinion of the score produced by the tool in relation to their clinical opinion of the person being assessed. Specifically, the health and care practitioners were asked "Do you feel this is an accurate reflection of this person's frailty risk?" and "In your opinion has the risk of frailty changed since completing the assessment?".

Regarding whether practitioners felt the outcome of the tool was an accurate reflection, in 102 out of 110 (93%) assessments the answer was "yes", and in 6 out of 110 (5%) the answer was "no". In two assessments this question was not answered (2%). This suggests that there was a high level of agreement between the practitioners' estimate of frailty risk and the outcome of the tool.

For 16 practitioners the score recorded was incorrect (including 1 who responded "no" to the tool providing an accurate reflection). This means that up to 23 practitioners (15+8) in total may have disagreed with the tool score (assuming that the correct score had been recorded). This gives a lower limit for agreement by practitioners of 79% (87/110). We can therefore say that between 79% and 93% of practitioners considered that the tool gave an accurate assessment, which is considered to be good evidence of validity of a scale.

In terms of whether the practitioner's initial estimate on frailty risk had changed having conducted the assessment, in 103 out of 110 (94%) assessments the answer was "no" and in 6 out of 110 (5%) assessments the answer was "yes". This question was not answered for one assessment (1%). The data for the 6 cases where the practitioner reported that their opinion had changed was investigated (see Table 5). In three out of the six assessments in which the opinion changed, the practitioner's opinion of frailty risk increased having conducted the assessment. In two of the assessments, the opinion on frailty risk decreased, and in one assessment the practitioner reported that their opinion changed however their rating did not change. This may have been due to an error when entering the data.

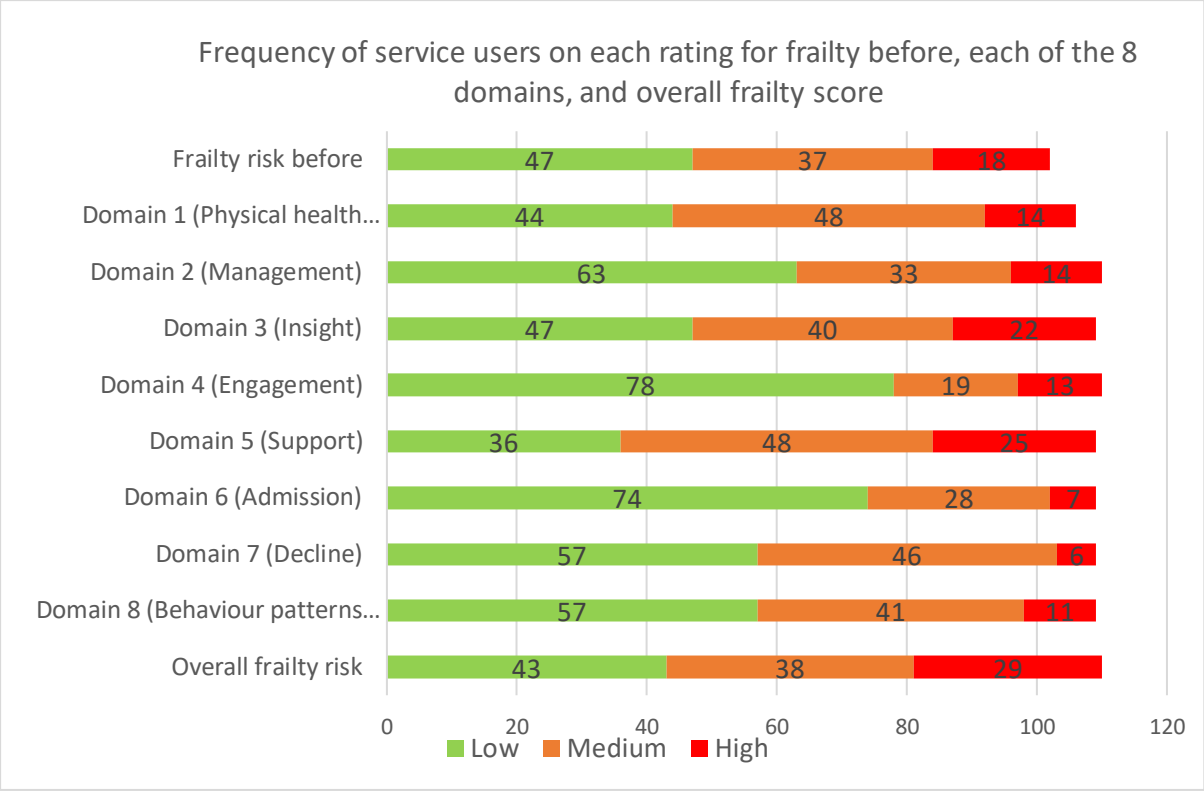

Figure 7: *Categorisation of frailty risk for (a) practitioner estimate, (b) the 8 domains of the tool and (c) overall risk of frailty according to the tool.*

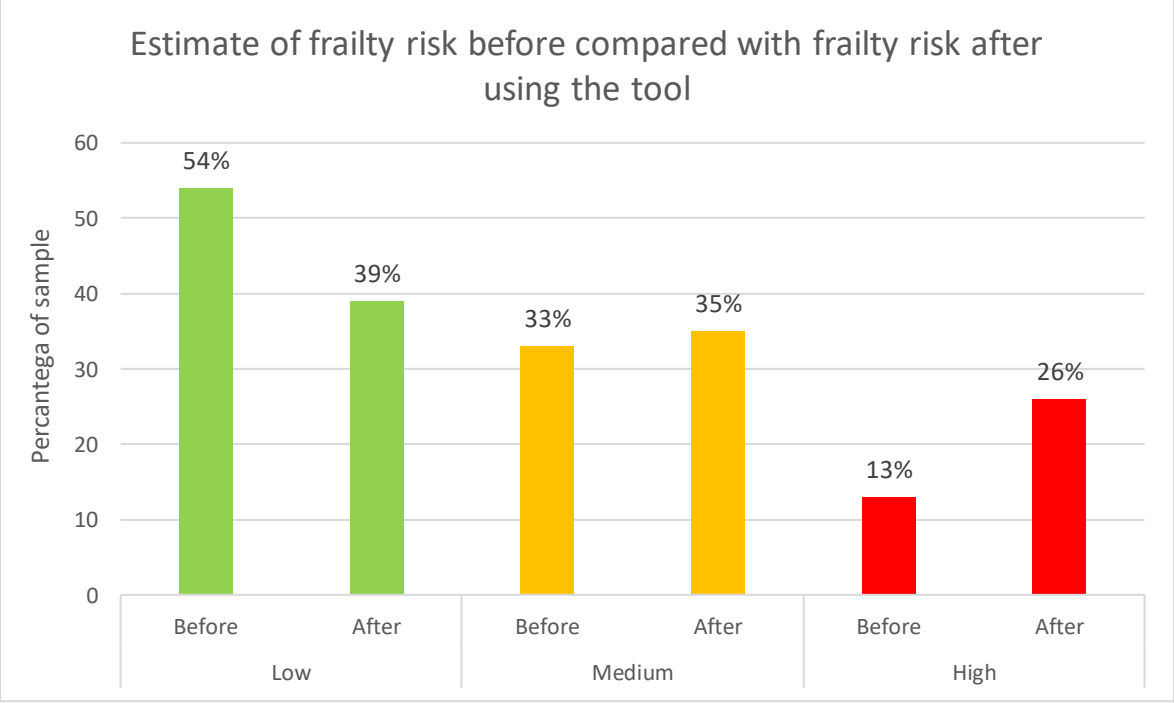

Figure 8: *Practitioner estimate of frailty risk compared to the tool outcome.*

There were 18 assessments where there was a difference between the practitioner's estimate prior to the assessment and the overall score on the risk assessment tool, but the practitioner reported that their opinion had not changed. On four of these, the tool indicated a lower risk than the assessor had thought, and for 14, the tool indicated a higher risk. There was one incident where the practitioner estimated the frailty risk to be high, however the overall frailty risk according to the tool was low. Upon further investigation, it seems the individual should have been categorised as high according to the scoring of the domains, therefore this may have been an error when entering the data onto the survey.

In general, it can be concluded that the practitioners' assessment of the person being assessed was in line with the score from the tool at a minimum for 79% of assessments and potentially as high as 93% of assessments. This range indicated a high level of agreement, indicating that the tool is providing information that is consistent with practitioners' conception of risk of frailty, and providing evidence supporting the validity of the tool.

Inter-rater reliability

A total of 25 of the people assessed received a second assessment with a different practitioner to investigate inter-rater reliability (see Table 6). As the assessments are ordinal in nature, inter-rater reliability was assessed using the Kappa statistic. Overall agreement was very poor. For the overall frailty risk assessment, the Kappa value (0.26) indicated very poor agreement between the practitioners. Across the eight domains only in the assessment of Decline (domain 7) did Kappa exceed 0.6 (kappa=0.65, $p<0.001$). For all other domains Kappa never exceeded 0.4 (poor agreement), and for domain 8 (behaviour and falls) the agreement is close to absolute chance.

The assessed scores across all domains are provided in Appendix P. The first assessor was predominantly a Learning Disability Nurse, and the second assessor was predominantly a Frailty and Falls Advanced Practitioner. In general, there was a tendency for the Advanced Practitioner to use the medium and high-risk category more predominantly than the Learning Disability Nurse, but less so for domains 4 (Engagement), 5 (Support), 6 (Admission), and 7 (Decline) where the agreement is higher. The relationship in domain 8 is much more mixed (i.e., close to random). When the Student Nurse, Community Care Officer and Healthcare Assistant are removed as the first assessors (22 repeated assessments), agreement improves marginally, but does not change the overall assessment of agreement.

Table 4: *Change in frailty risk before and after for 110 assessments.*

Frailty Risk before (practitioner estimate)	Frailty Risk after assessment (according to the tool)			
	Low	**Medium**	**High**	**Total**
No risk	12	0	0	12
Low	29	14*	4*	47
Medium	2*	24	11*	37
High	0	0	14	14
Total	43	38	29	110

Table 5: *Assessments where the practitioner reported their opinion to have changed.*

Individual assessed	Estimate before	Overall frailty score	Change from opinion before to opinion after	Opinion After	Practitioner comment
User 6	High	High	No change	High	"Different domains - the LD tool had some conflicting statements within the same box which made it a bit tricky"
User 50	Low	Medium	Increase	Medium	None
User 57	Medium	Low	Decrease	Low	None
User 83	High	High	Decrease	Medium	"[individual] has had Multiple falls and an admission to hospital. Although, some of this are attributed to mental state there is a risk of decline."
User 117	Low	Medium	Increase	Medium	None
User 130	Medium	High	Increase	High	"Service user has a sever learning disability with lack of engagement - however she does have care in place to ensure she is well managed and attends the relevant health services"

Note: This only lists cases where the clinician indicated that the assessment lead them to change their opinion of the risk for the individual being assessed.

Table 6: *Agreement between two practitioners for 25 people that were assessed twice.*

Domain	Kappa (se, z) p
Overall frailty risk	0.26 (0.15, 1.76) p=0.039
Domain 1 (Physical health conditions)	0.28 (0.14, 1.97) p=0.025
Domain 2 (Management)	0.39 (0.14, 2.8) p=0.0026
Domain 3 (Insight)	0.22 (0.13, 1.67) p=0.048
Domain 4 (Engagement)	0.37 (0.16, 2.36) p=0.009
Domain 5 (Support)	0.37 (0.17, 2.18) p=0.014
Domain 6 (Admission)	0.46 (0.18, 2.55) p=0.005
Domain 7 (Decline)	**0.65** (0.19, 3.26) **p<0.001**
Domain 8 (Behaviour patterns and risk of falls)	0.06 (0.13, 0.48) p=0.314

Note: For the Kappa statistic good agreement is generally indicated by values for kappa>0.75. Where the p value <0.05, this indicates that Kappa is not 0, but in general has little meaning for Kappa values below 0.6.

Interviews with health and care practitioners

Interviews were conducted with two practitioners. One had completed one assessment and the other had completed four, all had been with people with capacity to consent. Topics of significance that were raised in the interviews have been discussed below.

Training to use the tool

Both practitioners reported hearing about the training session through a team member and it being an expectation that the whole team attended training. Training was generally perceived well, although it was reported to be difficult to find the documents using Teams. Both practitioners reported that a check-in after the training would have been useful to recap and check that they had understood everything. This was particularly pertinent for one practitioner as they reported that the whole team had misunderstood an important procedural element during the training and then required additional training.

> *HCP 4965 – "Maybe another little check in would have been useful to see how people are getting on and a reminder, because obviously we are very busy."*

Perceptions of the tool and how it fits within their role

The tool was generally perceived to have a broader conceptualisation of frailty than the practitioners had previously considered, which they found helpful. They did consider frailty identification as part of their role but had not previously used any tools to do this.

> *HCP 4965 - "I mean there isn't really, as far as I know, any assessment tool that we use in terms of that [frailty]"*

> *HCP 6728 - "I would just ask about mobility, how people are getting around what aids and equipment, any adaptations, things like that".*

Both practitioners reflected that using the tool was relatively quick, but the associated procedures were too burdensome, including completing the online survey, explaining the easy-read information to the individual receiving an assessment and Mental Capacity Assessments which was a requirement for the pilot study.

> *HCP 6728 - "I'm not sure it feels right to do a capacity assessment on someone for the sake of some research".*

The current crisis for health and social care services seemed to exacerbate these feelings, as time and capacity was so limited.

> *HCP 6728 - "I don't know if this is the best time, and when everyone's got massive caseloads. And you know, you've got homes closing down and stuff like that. Just things that need to be pushed out urgently".*

Using the tool

Experiences of engaging and communicating with people throughout assessments varied, as one practitioner explained:

> *HCP 6728 - "With other people [people] it was a lot more difficult. One, particularly when you was reading the easy read, and it talks about death. That triggered, that, didn't like that at*

all. And then it was the reassurance that "you're not going to die" so I think it was very much dependent on the service user"

Some people who were assessed found the tool difficult to understand, and the concept of frailty was hard to explain, which contributed to the variability of experiences using the tool. One practitioner suggested an easy read version of the tool to support discussions.

HCP 4965 when asked about using the word 'frailty' with the individual who was assessed - "I probably did mention it, but I don't. Yeah it probably wouldn't be something I would normally use I must admit. I'd just be talking about her health… where she might, you know, needs a bit more support".

Both practitioners spoke about needing more guidance about what happens after an assessment, and who is expected to monitor any changes, in line with the tool.

HCP 6728 - "I'm like, well, now, what happens now?"

HCP 4965 - "It says about monitoring changes, but who monitors changes, me? The GP? You know maybe just that bit should be a bit more like "refer to the MDT"".

Using the tool did not lead to any different outcomes for any of the people assessed, even if the frailty risk assessment came out as higher than expected because practitioners felt that concerns were already being addressed, for example by referrals to specialist services.

The participating practitioners spoke about the tool not changing their view of the person, as the tool's domains were considered by other assessments or as part of their role. However, one practitioner emphasised that she still considered the tool helpful to support conversations around health.

HCP 4965 – "help you explore a bit more about the health and what they're doing about that health, and do they need any more support around that".

Use of the tool within the context of this service evaluation was seen by practitioners as a top-down process and being driven by managers, which they acknowledged was an effective way of getting people to use the tool. Considering wider use, one practitioner felt that the tool may be worth considering for those where there was a risk of frailty based on clinical judgement, but not for everyone with a learning disability.

HCP 6728 - "I think it's great in theory. If I did a review and someone seemed maybe.. there was a risk, I'd be more inclined to do it even if I needed to do a capacity assessment but obviously it's hard" (referring to time pressures)

One practitioner felt that the tool might be useful for those with physical health needs without a learning disability. One practitioner highlighted that they had spoken to many people drawing on services who had declined the tool and felt it may be better for people to opt-in after receiving a letter or for those with a learning disability nurse to be consulted about it.

Interview with a person drawing on services and carer

One person who was assessed and their partner, who was also their informal carer, participated in an interview, and topics of significance that were raised in the interview have been discussed below.

<u>Understanding of the term "frailty"</u>

Both the individual who had been assessed (hereafter referred to as 'individual') and carer had heard of frailty before and had some understanding around its meaning. In particular, the individual associated frailty with older age and becoming more limited regarding the activities one is able to do.

Individual - *"… getting old and can't do things like you used to".*

The individual reported that they would consider themselves frail, and their carer agreed with this. Both felt that health professionals had spoken to them about frailty before, and that this had probably been with the individual's assigned Learning Disability Nurse.

<u>The frailty risk assessment</u>

The assessment was carried out with the individual and carer over two months prior to this interview. Both did vaguely remember having the assessment when prompted, however they did not recall much of it.

Individual - *"It was about falls and things like that".*

When reminded about the domains covered on the risk assessment, the individual and carer felt that this covered the things that were important to them. This also prompted the carer to talk about a recent event where they had experienced a lack of communication from a healthcare provider as they do not use email, suggesting that healthcare communication may be important.

When asked how they felt about the results of the assessment, the individual commented *"I can't cope anymore or whatever… I'm not really sure"* and had not felt like this before the assessment. This may highlight a real need to manage any anxieties that may occur as a result of the assessment and to ensure there is a clearly communicated follow-up plan.

Neither the individual nor carer were aware of any changes to care that had happened as a result of the assessment. The individual had recently received treatment for an ongoing medical condition, which had had a positive impact on their quality of life, but it was unclear whether that was a result of the frailty assessment. When asked about whether they thought having the assessment was helpful, the individual said yes and said they would perhaps want another assessment in future. The carer was keen for the individual to have another assessment in future, feeling that it may be helpful for getting an idea of the individual's health status.

Carer – *"It gives an overview of what is going on".*

Conclusions and lessons learnt from Phase 1b

The aim of Phase 1b was to build on the knowledge obtained from Phase 1a with a larger group of participants, provide an indication of inter-rater reliability and external validity of the scale, and obtain feedback on the use of the tool. 110 people were assessed out of a target 200. The demographics of the people assessed in Phase 1a were similar to Phase 1b.

When checking scores it was found that 19% of all assessments conducted in Phase 1b did not have the correct score according to the criteria, and therefore needed to be corrected prior to analysis. Regarding overall risk of frailty for the sample, 39% were categorised as low risk according to the

tool. The domains of Support and Insight received the highest number of high-risk ratings out of all the domains, which was consistent with Phase 1a. Engagement presented the lowest risk, with 71% of people assessed receiving a low-risk rating for this domain. There was a difference between frailty risk before the assessment (as judged by practitioner's estimate) and frailty risk as indicated by the tool for 31 of the 110 (22%) initial assessments. Of these 31 assessments, four changed from low to high, a considerable change in frailty risk. Although the tool resulted in a different frailty risk to the assessors' prior opinion in 22% of cases, when asked, only 5% of assessors reported the tool changing their opinion on frailty risk.

One issue that became apparent when interpreting potential changes of opinions was that some of the comments provided by assessors were difficult to interpret. For example, in some cases the assessor claimed that their opinion had changed, however having looked at their answers we could see no change in estimated frailty risk before and their opinion after. For this reason, it is difficult to interpret some of these results.

In some assessments, the practitioner claimed that their opinion had not changed, however the reported frailty risk estimate before conducting the assessment and their estimate after are different. It is possible due to the ambiguity of the question that there could have been varied interpretation of its meaning depending on the assessor. Potentially assessors may have understood the question "In your opinion has the risk of frailty changed since completing the assessment?" as the people risk changing in the time between them conducting the assessment and the time when they were inputting the data onto the Smart Survey. This is unlikely as the Smart Survey would likely have been completed on the same day as the assessment, however if a further evaluation was conducted, this question could be reworded.

A total of 25 people were assessed twice by two different practitioners to investigate inter-rater reliability, one of the main objectives of phase 1b. From the analysis it was found that the assessors were in agreement on overall frailty risk on 16 out of the 25 assessments (64%), which is generally considered as low agreement. We also investigated the agreement on the eight domains and found these to vary considerably, however there were four domains (1,2,3 and 8) where assessors were not in agreement over 50% of the time.

When obtaining feedback via interviews, practitioners highlighted that frailty identification fitted within their role and frailty was also a concept that was familiar to the individual and carer that were interviewed. Practitioners involved the individual being assessed and their support network in the assessment, and therefore they felt that the tool needed to be more accessible and understandable, and additional resources to support this may be useful in the future. Undertaking the risk assessments did not change the practitioners' views on frailty risk for the people they assessed and they did not make any referrals following the assessment. However, HCC later reported that 12 referrals were made which would otherwise not have happened by practitioners that did not participate in the focus group. Despite the assessment not changing their views or practice, the practitioners interviewed in phase 1b thought it may be helpful for some people they worked with. The individual and carer interviewed also felt it was useful and that they would want an assessment again in the future, despite the individual describing distressing feelings about their level of risk and not knowing if anything had been done differently as a result.

The process of undertaking the frailty risk assessments and the evaluation procedures meant that the assessments were seen as time-consuming by practitioners, particularly in the context of service pressures. The practitioners understood the importance of completing assessments for the overall

service, but this was necessarily balanced against their core workloads. This led to individuals completing a small number of assessments and/or only completing the assessments for 'less complex' cases (i.e., those who did not require a best interest assessments), and we suggest that these factors likely contributed to not meeting the target number of assessments.

Engaging participants for focus groups was a continued challenge for Phase 1b despite the addition of one page summary sheets to try and increase engagement. Although over 50 health and care practitioners were trained in using the tool, we were only able to obtain feedback from two staff members. It is possible that although over 50 practitioners were trained, not all may have had the opportunity to conduct an assessment and therefore did not volunteer to participate for this reason. We also acknowledge that the pressures experienced by clinical and social services are likely to have led to practitioners not having time in their workload to undertake interviews or focus groups. Recruiting people who received an assessment and carers was also a challenge in Phase 1b. Despite eight people and three carers saying they were happy to be contacted, the majority did not respond when we reached out and ultimately, we were only able to conduct an interview with one person drawing on services and their carer.

Conclusions

To conclude, during Phase 1b of the pilot study, 110 people were assessed and we were able to explore the use of the tool through the three objectives. The data indicated that over 60% of those assessed were at medium (35%) or high (26%) risk of frailty.

In general, as a whole the scale scores are distributed across the scale range and are in line with previously published literature. Where the current tool assesses *risk* of frailty, and other commonly used tools assess frailty, the data presented here in terms of people assessed as being at medium to high *risk* of frailty is in line with what may be expected given the published estimates of people who have moderate or severe frailty. In addition, health and care practitioners indicated that the tool produces assessments that between 79% and 93% of occasions is in line with their clinical assessment. Taken together the data provides evidence of internal reliability (the measurement properties) of external validity (the clinical assessment) for the tool.

However, there is also a concern that the tool was not scored correctly on a number of occasions, and that there was a lack of agreement between different assessors when assessing the same person (the reliability of the tool). This indicates that there is a significant need for training to ensure that practitioners score the tool correctly, and further testing to ensure that consistent scoring can be achieved between different practitioners. We were able to obtain feedback from two practitioners, one person assessed and one family carer. We had hoped to speak with more than this but due to challenges with recruitment this was not possible. Overall feedback seemed to be that although assessments did not lead to immediate changes in care i.e., a referral, it did increase awareness around frailty as a concept and the importance of early identification and monitoring of risk in this population.

Overall conclusions

A pilot evaluation of a novel tool for assessing frailty risk assessment for people with learning disabilities was undertaken. This report is divided into two sections: Phase 1a, which assessed 52 people and Phase 1b, which assessed 110 people using the Frailty + Learning Disability Risk Assessment Tool in Hertfordshire County Council. In Phase 1a, 42% of service users were female with 48% in Phase 1b, compared to 51% of the general population of Hertfordshire. The majority of service users were White British in both Phases; 98% in Phase 1a and 90% in Phase 1b which is higher than the Hertfordshire general population (80.8%).

Regarding frailty risk, outcomes were similar across Phase 1a and Phase 1b. A promising result from Phase 1b was that between 79% and 93% of practitioners stated that they agreed with the outcome of the tool. In Phase 1a it was found that in 15% of assessments, practitioners stated that their opinion changed as a result of using the frailty tool whereas in Phase 1b this was only 5%. However, it was found that in 22% of assessments in Phase 1b, there was change between the practitioners' estimate of risk prior to using the tool and the outcome of the tool.

A real strength to this pilot study was that we were able to investigate inter-rater reliability in Phase 1b through 25 people being assessed twice by two different practitioners. Interestingly, it was found that the assessors agreed on the outcome of the tool only 48% of the time, with some of the domains having even lower levels of agreement. For certain domains such as Engagement, this may be understandable as how much an individual engages may be difficult for a practitioner to determine if they are not familiar with the individual. However, for domains such as Physical Health Conditions and Admission, it is perhaps surprising that the levels of agreement were low. As the majority of inter-rater reliability assessments were conducted by an advanced practitioner and a learning disability nurse, it is possible that these findings were down to potential differences in risk perception, however whether this is due to differences in profession or individual differences is unclear, with previous research highlighting individual differences affect risks identified more than profession (Stone, 2019). How familiar the practitioner was with the person being assessed may have also had an influence, as the second assessor was often less familiar with the person being assessed which may have contributed to the differences in opinions.

Notably, 19% of the Phase 1b assessments did not correctly categorise overall frailty risk score. As data was not recorded about who completed which assessment, it was not possible to determine whether it was a small number of practitioners who misunderstood the scoring criteria or a greater number of practitioners. This implies that for any future use of this tool, the criteria for scoring overall frailty risk based on the domain may need to be clearer. We recognise that some of these incidents of false scoring may have been down to selecting the incorrect category when inputting data on the Smart Survey. Therefore, if the survey is used again, it would be beneficial for it to automatically calculate the overall score once the data has been entered, as this would eliminate any mistakes occurring.

Feedback on the training was generally positive, with mixed views around whether online or in person is preferred, however this is to be expected based on individual learning preferences. Additional check-ins from the core team to practitioners after the initial training may also be helpful in the future. It was clear from our interviews and focus groups with health and care practitioners that they felt frailty was important and relevant to their role, and that the tool had raised their awareness around risk of frailty and its potential to affect those people with learning disabilities of a younger age. Notably, none of the practitioners across Phase 1a and 1b reported their opinion or

actions changing as a result of using the tool, even where the tool predicted a higher risk of frailty than they had originally thought. In line with this, the individual assessed and carer were also unaware of any changes due to the tool.

For some practitioners, it seemed that the tool was seen as assessing frailty, rather than risk, and this affected people's opinion of the outcome of the assessment and how it may be used in routine practice. It seemed that some practitioners were unsure about what was expected after the assessment, such as who then continues to monitor the individual. If further tool use is recommended, increased guidance and support around this in future may be beneficial. Importantly, these experiences may not be representative as only four practitioners were consulted in this evaluation whereas there had been more conducting assessments.

Across the qualitative workstream in both phases, practitioners spoke about the considerable demands on their services and that this made it difficult to complete assessments within the required timeframe. Training and assessments were generally completed because it was seen as important to the overall service. Although there were differences in opinions in how the tool could be used in future, generally practitioners, along with the individual and carer, felt there was a place for the tool, but careful consideration would need to be given about balancing service expectations, team capacities and benefit to people drawing on services.

A limitation of the study was that recruitment was found to be a challenge. In Phase 1a the target was reached for number of assessments, however in Phase 1b this fell short of the target by 90 people even after a short extension for data collection. The service was extremely busy and under significant demand, and practitioners' workloads may have been unable to accommodate additional tasks, as supported by the qualitative data. Another issue with the data collected was the lack of diversity among participants. Most people assessed were White in both phases and this was a greater proportion than the general Hertfordshire population. Therefore, in any future phases it would be advantageous to include participants from a range of backgrounds including ethnic minorities, as well as increase demographic data collection to other variables such as sexual orientation and marital status.

Recruiting people who had received an assessment, carers and health and care practitioners for focus groups was difficult both in Phase 1a and Phase 1b and we did not meet our target number of participants in either phase. Again, with regards to practitioners, as their workload was high, perhaps they felt they did not have enough time to participate or simply missed the email in which this information was shared. The changes made to the information sheets for service users and carers resulted in more people stating that they were happy to receive further information, but the research team were then unable to speak with the majority. It is widely acknowledged that recruiting people with learning disabilities and their paid/unpaid carers is challenging and time-consuming, and it is likely that we needed more time to follow up with people.

To conclude, this service evaluation of the novel Frail + Learning Disability Risk Assessment tool has demonstrated that there is some evidence to support the reliability and the validity of the tool (the scores are in line with other published reports and agree with practitioners' assessments). There is more work to do to understand why there is a lack of consistency across different practitioners (the reliability of the scoring), and to ensure that the correct score is assigned at the end of the assessment. In addition, the qualitative assessment provided evidence of frailty being of interest to practitioners working with people with learning disabilities, people with learning disabilities and

carers. All participants of the qualitative aspect of the study highlighted that using the tool had raised their awareness around frailty.

Recommendations and potential next steps
1. Consider developing an accessible version and/or guidance of the tool for use with people who are receiving an assessment and carers. This would benefit from input from experts by experience.
2. Consider how to ensure scoring in line with instructions, including potential modifications to training, ongoing supervision and how the scoring criteria is presented on the tool itself.
3. Explore potential reasons for the low inter-rater reliability. This may involve a focus group of different practitioners discussing case examples and rationale for scoring.
4. Capture information about actions resulting from the assessment and medium to long term impact of tool use. Systematically collected long-term outcome data and/or case study examples would be helpful here.
5. Gather views from practitioners and people who have received an assessment. This may require a different approach to interviews/focus groups e.g., a short questionnaire shared online or via post.
6. Further data collection (increasing the sample size) would enable evaluation of the scale structure and inform judgement on internal validity. This would support development of training on how to use the tool.
7. Future evaluation could consider comparing the use of different frailty tools with the same group of people to provide evidence of external validity of the Frail + Learning Disability Risk Assessment tool. Diagnostic frailty assessment tools designed for people with learning disabilities include the ID-Frailty Index, or the HC-IDD Frailty Index.

Acknowledgements

The team at the University of Hertfordshire were the authors of this report and designed the service evaluation and carried out quantitative data analysis and qualitative data collection and analysis. The conclusions reflect our views and may not reflect the views of Hertfordshire County Council and EAHSN.

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Appendix

Appendix A – The Frailty + Learning Disability Risk Assessment Tool

FRAIL+LD - FRAILTY INDICATORS FOR PEOPLE WITH LEARNING DISABILITIES

eQUALITY for people with learning disabilities

Hertfordshire

These risks should be considered where indicated for any patients with learning disabilities aged 18 and above to enable more proactive management of changes to health.
People with Learning disabilities are at increased risk of vulnerabilities relating to unquantified changes to health due to growing older.

Name:	DOB:	NHS no:

Indicators	Level of risk					
	Low	Tick √	Medium	Tick √	High	Tick √
Physical Health Condition	• No known physical health condition **or** 1 physical health condition that is managed well		• 2 health conditions requiring regular reviews - e.g. swallowing problems, nutritional deficit, prone to infections		• More than 2 unstable health conditions	
Management	• No known physical health condition **or** health issues managed with medication and adequate support e.g. specialists		• Health condition requiring reviews beyond annual health check • Stable health not sustained		• Significant health needs combined with a history of behavioural challenges that are complex to manage. • Unmet needs	
Insight	• No known physical health condition **or** has good insight into condition • Able to take necessary actions with **or** without support		• Has a change or decline in level of insight into own health issues • Able to take health advice or engage with necessary actions with support		• Has no insight into own health needs • Declines opportunities to establish level of insight • Non-compliant with care and unaware of health decline.	
Engagement	• Engaging well • Attends regular health services e.g. GP, dentist, annual health checks, takes prescribed medication		• Not engaging with health recommendations e.g. poor dietary and lifestyle choices • Fluctuates in accessing health care services • Lack of proactive staff support		• Lack of engagement – not attending health appointment, declining health support, DNAs • Non-compliant with care • Self-neglect poor hygiene, not reporting health decline. • Declines all support – health needs unmanaged	
Support	• Living independently **or** with minimal support and coping well		• Increase in support needs required **or** decline in ability to carry out own support needs • Significant mobility issues • Change in health needs puts suitability of usual placement at risk		• Requiring 24hour support for complex physical health needs • Change in baseline now requiring support with all ADL • Unmanaged needs putting placement at risk	
Admission	• No unplanned admissions in the last year		• 1 - 2 unplanned hospital admissions in the last year **or** changes to usual routine health monitoring		• More than 2 unplanned hospital admissions in the last year **and/or** significant changes to health baseline	
Decline	• No recent major health decline		• Health has declined in the last year		• Health has declined in the last month	
Behaviour patterns & Risk of Falls	• Patterns of behaviour do not pose any additional risks to health • No falls		• Behaviour patterns contributing directly to health risk • 1 – 2 Falls in a year		• Known safeguarding history (health related) • High incidence of falls - more than 2 in a year	

Recommendations:

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Appendix B – HaCP Full Information Sheet (Phase 1a)

Title of study: Assessing risk of frailty in individuals with Learning Disabilities.

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. If you have any questions about the study, please contact the lead researchers, whose details are at the end of this information sheet. Your participation in this study is voluntary. If you do agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs (after accessing this website, scroll down to Letter S where you will find the regulation)

What is the purpose of this study?

Frailty has been defined as "a medical syndrome ... characterised by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death." (Morley et al., 2013). Studies have found frailty to affect individuals with a Learning Disability on average 20-30 years earlier than what is expected in the general population, which can lead to early mortality. It has been estimated that early deaths could be prevented if frailty is identified in the early stages and appropriate plans are implemented.

Currently there isn't a suitable tool to assess risk of frailty in individuals with Learning Disabilities and therefore we want to test the effectiveness of a novel tool that has been developed. The aim of the tool is to detect risk of frailty and make appropriate actions to reduce impact on physical health in the future.

You have been invited to participate in this study because you have been using this novel tool to conduct assessments in the last couple of months. We are interested to see how you have found using the tool and any suggestions or feedback you have for further developments in the tool itself, resources and further training.

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You

are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not have any consequences.

How long will my part in the study take?

The study itself will take a couple of hours. After this we may contact you if we need to clarify any further information.

What will happen to me if I take part?

You will first be asked to read and sign a consent form to indicate that you are happy to participate in the study. Following this, you will be invited to participate in a focus group with other health and care practitioners from Hertfordshire County Council who have also been using the tool to complete assessments. The focus group will be either face to face on Hertfordshire County Council premises or conducted online via a video platform. You will be given an official invite with the date, time and location of the focus group.

Upon arrival, you will be seated around a table with others participating if the focus group is conducted in person. The researchers will introduce themselves and provide a short overview of the focus group and answer any questions you may have. They will check that you are happy to be recorded. The focus group will take approximately 2 hours and will involve answering questions and having discussions about the tool.

If you are invited to an interview, you will be seated with a researcher who will be conducting your interview. They will introduce themselves and provide an overview of the purpose of the interview and answer any questions you may have. They will check that you are happy to be audio recorded. The interview will take up to 1 hour and will involve answering questions relating to the assessment tool and its potential impact on the support the individual you care for receives.

What are the possible disadvantages, risks or side effects of taking part?

We do not foresee any disadvantages or risks of taking part in the study.

What are the possible benefits of taking part?

Frailty is a significant factor when considering early mortality that could be prevented if adequate measures are taken. As previously mentioned, there currently isn't a suitable tool to assess frailty in individuals with Learning Disabilities. By providing feedback on your experiences of using the tool, you are contributing towards the development of a tool that could be applied widely throughout the county and beyond to support individuals who may be at risk of frailty.

How will you ensure risks of Covid-19 are minimised?

For any meetings or focus groups we will ensure that the latest guidelines are followed. We will talk to you about your needs and wishes before any meetings go ahead.

How will my taking part in this study be kept confidential?

Consent forms are not anonymised, however they will be kept on a secure electronic database and destroyed within a year of study completion. All other information collected throughout the study will be kept strictly confidential and we follow ethical and legal practices. Names will not be included on our data, instead we will use anonymised numbers

so that people cannot be identified or recognised. Anonymised quotes may be used in reports and presentations, however identifying information will be removed.

Information will be stored electronically on a secure database which will be password-protected, and only authorised research personnel will have access to this. Data will be kept for a period of 5 years and then destroyed after this time.

Audio-recordings will be transcribed and identifiable information (e.g., names) will be removed. The audio-recordings will be kept in a password protected file at the University of Hertfordshire.

Will the data be required for use in further studies?

The data obtained from this study will be analysed, written-up and submitted for publication in an academic journal, and used in a grant application for a larger, longitudinal, study. The data collected may be re-used or subjected to further analysis as part of a future ethically-approved study; the data to be re-used will be anonymised.

Who has reviewed this study?

This study has been reviewed by The University of Hertfordshire Ethics committee who have approved it to be suitable. The UH protocol number is LMS/SF/UH/04841

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with **Dr David Wellsted** (contact details: University of Hertfordshire, College Lane, Hatfield, email: d.m.wellsted@herts.ac.uk) or **Dr Silvana Mengoni** (contact details: University of Hertfordshire, College Lane, Hatfield, email: s.mengoni@herts.ac.uk)

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

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Appendix C – HaCP Participant Consent Form (Phase 1a)

Participant ID:

Study title: Assessing risk of frailty in individuals with Learning Disabilities

- ❑ I have read the associated Participant Information Sheet and had the purpose and nature of the study explained to me in writing.
- ❑ I have had the opportunity to ask any questions about the study.
- ❑ I understand that participation involves taking part in a focus group to discuss an assessment tool with other health and care practitioners also working for Hertfordshire County Council.
- ❑ I agree to the focus group being audio-recorded.
- ❑ I understand that all information I provide for this study will be treated confidentially.
- ❑ I understand that if I decide to withdraw, no further data will be collected and previous data will be deleted where possible.
- ❑ I understand that anonymised data (e.g., recordings, transcripts) will be stored electronically on a secure database and kept for a period of 5 years, after which they will be destroyed.
- ❑ I voluntarily agree to take part in this research study.

Name of participant: ….....

Signature of participant: ….....

Date: ….....

Name of researcher: ….....

Signature of researcher: .....

Date: .....

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Appendix D – HaCP Focus Group/Interview Topic Guide (Phase 1a)

Welcome

Welcome participants and thank them for agreeing to take part in the focus group.

Ask participants to turn off their mobile phones. Explain the procedure in the event of a fire and give the location of the nearest toilets.

Moderator(s) introduce themselves and explain their roles.

Introduction

As you know, the purpose of today's discussion is to hear about your experiences of conducting assessments using the newly developed frailty tool and gather your views on the tool so that it can be improved for future assessments. We are keen to hear everyone's views and to learn about differences if your experience, as well as similarities. There are no right or wrong answers. Please don't be afraid to offer negative as well as positive views of the tool, and to disagree as well as agree with others in the group.

We're hoping for a relaxed group discussion, so feel free to respond to me and other members of the group without waiting for me to call on you. However, for the benefit of the transcriber, please try to make sure that only one person talks at a time if possible.

Ask the group if there are any final questions before getting started, and address any questions asked.

Check that everyone in the group is happy for the recorded to be turned on and then start the recorder.

Icebreaker

Could we start by going around the room, introducing yourself, where you are based and your role.

Questions

1. Do you feel that the training prepared you to use the frailty assessment?

- Initial and ongoing training
- Training content; format; timing
- Prior knowledge of frailty in this population
- Experience of assessing/considering frailty
- Any improvements

2. What did you think about the process of using the frailty assessment?

- Questions included in the tool
- How the tool was used with service users
- Perceptions of service users/families/support staff
- What helped/hindered tool use?
- Was it similar to use with different service users?
- Any improvements?

3. Did the frailty assessment support your clinical role?

- How did the results align with their previous views about frailty of their service users? – If different, what did they think about this
- How did they make judgements of frailty beforehand? What helped make the decision?
- How does this assessment align with other assessments/clinical care they deliver? How did they inform judgement beforehand?
- Have they done anything differently as a result of using the frailty assessment? E.g., treatment/support, if so, do they feel it has made an impact?

Close

Before we finish, is there anything else about your experiences of conducting frailty assessments that would be useful to know?

Thank the participants for their time and for sharing their experiences and opinions.

Explain what will happen to the focus group data and how the findings will be used.

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Appendix E – People who draw on Services One Page Information Sheet (Phase 1b)

Frail + Learning Disability Risk Assessment Tool

Our names are Dominique Grohmann and Silvana Mengoni. We are researchers at the University of Hertfordshire.

A member of staff has looked at changes that have happened in your life and body. This is called the Frail + Learning Disability Risk Assessment tool and it helps them to plan what support you might need now and in the future.

We would like to talk to you and find out what it was like having this check and if it was helpful for you.

If you would like to find out more, please contact us. If there is anything else you want to know, you can contact Silvana.

Email address: s.mengoni@herts.ac.uk

Contact number: 01707 284 494

Appendix F – Carer One Page Information Sheet (Phase 1b)

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Information Sheet for Carers & Support Workers

We'd like to hear your thoughts on the Frail + Learning Disability Risk Assessment tool

- We are a research team at the University of Hertfordshire, and we are inviting you to participate in a focus group.
- A service user you support was recently assessed using a newly developed frailty risk assessment tool. We are looking to obtain feedback on the tool to see if there are any improvements or changes we can make.
- This focus group is for service users who have been assessed, as well as carers of service users who were assessed.
- It will involve answering questions relating to the assessment tool and its potential impact on the support that the individual you care for receives.
- The focus group will take up to 1.5 hours and will be either via an online platform or face to face on Hertfordshire County Council or University of Hertfordshire premises.
- If you are interested in participating or would like more information, please contact Dominique Grohmann or Silvana Mengoni.

Contact details

Dominique - d.grohmann@herts.ac.uk
Silvana - s.mengoni@herts.ac.uk or 01707 284494

Appendix G – People who draw on Services Full Information Sheet (Phase 1b)

Frail + Learning Disability Risk Assessment Tool

In this easy read document, difficult words are in **bold.** We explain what these words mean in the sentence after they have been used.

Who are we?

We work at the University of Hertfordshire and Hertfordshire County Council.

We are a team of **researchers** and **professionals.**

Researchers are people whose job it is to find out new things to help people.

Professionals are members of staff, such as support workers, social workers and nurses.

We want to find out new things so that we can help people with learning disabilities.

What do we want to find out?

Professionals have looked at changes that have happened in your life and body to help guide the way support is planned for you now and in the future.

They completed a form with you and asked you some questions to see if you might need more support.

We want to see if having this completed was helpful for you.

How will we find things out?

We will do an **interview** or a **focus group**.

A **focus group** is when a group of people are asked questions about something.

An **interview** is just a chat between you and a researcher.

Everyone doing the **focus group** or **interviews** has had a staff member complete this form with them.

What will happen in the interview or focus group?

The **interview** or **focus group** will be in person or online depending on what you prefer.

It will be in January or February 2023.

If the **focus group** is in person everyone will sit around a table.

If it is online, you can use a computer or a tablet. You will be given a guide on how to join the **focus group** online. We can practice this before if you like.

We will ask you questions about the form that was completed with staff.

We will also ask you questions about the support you are getting and any future support you may need.

Don’t worry if you don’t know the answer to all of the questions.

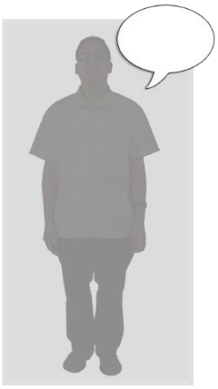
You can choose not to answer all the questions if you feel anxious or worried.

If you need a break, you can stop taking part at any time, just let the **researcher** know.

You can choose to bring someone with you that you feel comfortable with.

The **interview** or **focus group** may take up to 2 hours. It probably won’t take all of this time.

We will record the **interview** or **focus group** so that we can remember what everybody has said.



No one will be able to know it is about you in any reports we make.

We will change some of the information you give us, like your name, so that it is **confidential.**

Confidential means it is kept private and will not be told to anyone else.

The only time we may not be **confidential** is if we are worried about something you tell us, so we might need to talk to someone else.

For example, we might be worried that you are in danger, or that someone else is in danger.

Saying “yes” or “no”

You do not have to take part.

It is your choice. It is up to you to decide.

You can talk to other people to help you choose.

If you want to take part we will ask you to sign a consent form.

This means saying “yes, I agree to take part”.

If you do not want to take part you can say “no”.

Saying “no” will not change how people treat you. Your support plan will still be followed.

You can change your mind at any time. To do this you can contact us to tell us

What happens after the interview or focus group?

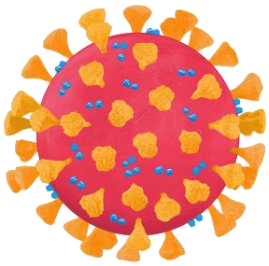
We will type up the information you gave us onto a computer.

This information will be stored on a secure database. This means it is safe.

This information will be **anonymous** – this means no-one will know it is about you.

We might write about things that you said in reports. We won't use your name in these reports.

What if I am worried about COVID-19?



COVID-19 is also called Coronavirus. It is an illness that has spread around the world. It can affect your lungs and breathing.

For any meetings in person we will make sure that the latest guidelines/rules to keep safe from **COVID-19** are followed.

We will talk to you about your needs and wishes before any meetings go ahead.

For example, wearing a mask or having hand sanitiser available.

Who can I speak to if I need support afterwards?

If you feel you need support after the **focus group** or **interview**, you can speak to your support worker, nurse or social worker.

Thank you for taking the time to read this document.

Contact Details

If you have any questions, you can contact the team who work at the University of Hertfordshire.

Their contact details are below.

They all work on this project and would be happy to speak with you if you have any questions.

	**Silvana Mengoni** email: s.mengoni@herts.ac.uk phone number: 01707 284 494
	**Dominique Grohmann** email: d.grohmann@herts.ac.uk
	**David Wellsted** email: d.m.wellsted@herts.ac.uk

University of Hertfordshire UH

Appendix H: People who draw on Services Consent Form (Phase 1b)

Study title: Assessing risk of frailty in individuals with learning disabilities

Please circle		
 YES	 NO	I have seen the information sheet.
 YES	 NO	I have met with a researcher to talk about the project.
 YES	 NO	I have been able to ask questions about the project.
 YES	 NO	I know what I will be asked to do to help find things out.
 YES	 NO	I know that I can say "no" to taking part at any time in the project.
		

YES	NO	I know that this means I can stop at any time in the interview or focus group. I can also tell the researchers at any time if don't want to take part anymore.
 YES	 NO	I know that information about me will be "confidential" – this means private. However, I know that if the researchers are worried about me or someone else, they might need to talk to someone else.
 YES	 NO	I know that the researchers will record the interview or focus group.
 YES	 NO	I know that the researchers will type things up. This might be things that I say, or questions that I answer. I know that the researchers will not use my real name.

 YES	 NO	I know how to contact the researchers.
 YES	 NO	I say "yes" to taking part in the project.

My name is ……

Signed here: ……

Date: ……

Researcher's name ……

Researcher's signature……

Date: ……

Appendix I: Carer Full Information Sheet (Phase 1b)

Title of study: Assessing risk of frailty in individuals with learning disabilities: a pilot study

We would like to invite you to take part in our study. Before you decide, we would like you to understand why the study is being conducted and what it would involve for you. If you have any questions about the study, please contact the lead researchers, whose details are at the end of this information sheet. Your participation in this study is voluntary. If you do agree to

take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs (after accessing this website, scroll down to Letter S where you will find the regulation)

What is the purpose of this study?

Frailty has been defined as "a medical syndrome ... characterised by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death." (Morley et al., 2013). Studies have found frailty to affect individuals with a learning disability on average 20-30 years earlier than what is expected in the general population, which can lead to early mortality. It has been estimated that early deaths could be prevented if frailty is identified in the early stages and appropriate plans are implemented.

Currently there isn't a suitable tool to assess risk of frailty in individuals with learning disabilities and therefore we want to find out what it is like to use a new tool that has been developed by Hertfordshire County Council. The aim of the tool is to detect risk of frailty and make appropriate actions to reduce impact on physical health in the future.

We would like to talk to people who have been providing support for an individual with a learning disability who has recently been assessed using this novel tool. We are interested to see how they found having an assessment done and any feedback you may have.

Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. If you decide to withdraw from the study, this needs to be done no later than a week after your participation in order for your information to be deleted. You do not need to provide a reason for your withdrawal.

How long will my part in the study take?

The study itself will take a maximum of 1.5 hours. After this we may contact you if we need to clarify any further information.

What will happen to me if I take part?

You will first be asked to read and sign a consent form to indicate that you are happy to participate in the study. Following this, you will be invited to participate in either an individual interview, or a focus group with service users who were assessed, as well as other carers who also provide support for someone with a learning disability who was assessed using the

tool. The interview or focus group will be either face-to-face on Hertfordshire County Council or University of Hertfordshire premises, or conducted online via a video platform.

If you are invited to an interview, a researcher will conduct your interview. They will introduce themselves and provide an overview of the purpose of the interview and answer any questions you may have. They will check that you are happy to be audio recorded. The interview will take up to 1 hour and will involve answering questions relating to the assessment tool and its potential impact on the support the individual you care for receives.

If you are invited to a focus group, then this will take place with other carers, support workers and people with learning disabilities. A researcher will introduce themselves and provide a short overview of the focus group and answer any questions you may have. They will check that you are happy to be audio recorded. The focus group will take up to 1.5 hours and will involve answering questions and discussing the potential impact of the assessment on support the individual you care for receives.

What are the possible disadvantages, risks or side effects of taking part?

We do not foresee any disadvantages or risks of taking part in the study.

What are the possible benefits of taking part?

Frailty is a significant factor when considering early mortality that could be prevented if adequate measures are taken, but there currently isn't a suitable tool to assess risk of frailty in individuals with learning disabilities. By providing feedback on behalf of the individual who was assessed and your own opinions on the use of the tool, you are contributing towards the development of a tool that could be applied throughout the county and beyond to support individuals who may be at risk of frailty.

How will you ensure risks of COVID-19 are minimised?

We will ensure that the latest national guidelines are followed. We will talk to you about your needs and wishes before any meetings go ahead.

How will my taking part in this study be kept confidential?

Consent forms are not anonymised, however they will be kept on a secure electronic database and destroyed within a year of study completion. All other information collected throughout the study will be kept strictly confidential and we follow ethical and legal practices.

Audio-recordings will be transcribed and identifiable information (e.g., names) will be removed. The audio-recordings will be kept in a password protected file on the University of Hertfordshire SharePoint, with only authorised research personnel having access to this. Audio-recordings will be deleted when data analysis has been completed.

Names will not be included on our transcripts, instead we will use anonymised numbers so that people cannot be identified or recognised. Anonymised quotes may be used in reports and presentations, however identifying information will be removed.

Information will be stored electronically on The University of Hertfordshire SharePoint, and only authorised research personnel will have access to this. Transcripts will be kept for a period of 10 years and then destroyed after this time.

Will the data be required for use in further studies?

The data obtained from this study will be analysed, and submitted for publication in an academic journal, and used in a grant application for a larger, longitudinal, study. We also intend to share the results of the study more widely, for example via talks, newsletters, press releases and social media. The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised.

Who has reviewed this study?

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology ethics subcommittee who have approved it to be suitable. The UH protocol number is LMS/SF/UH/05128.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with **Dr David Wellsted** (contact details: University of Hertfordshire, College Lane, Hatfield, email: d.m.wellsted@herts.ac.uk), **Dr Silvana Mengoni** (contact details: University of Hertfordshire, College Lane, Hatfield, email: s.mengoni@herts.ac.uk, phone: 01707 284494) or **Dominique Grohmann** (contact details: d.grohmann@herts.ac.uk).

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

University of Hertfordshire UH

Appendix J: Carer Consent Form (Phase 1b)

Participant ID:

Study title: Assessing risk of frailty in individuals with learning disabilities

- I have read the associated Participant Information Sheet which explains the purpose and nature of the study.
- I have had the opportunity to ask any questions about the study.
- I understand that participation involves taking part in a focus group or an interview to provide feedback on an assessment tool someone I care for was recently assessed with.
- I agree to the focus group or interview being audio-recorded.
- I understand that all information I provide for this study will be treated confidentially.
- I understand that if I would like to withdraw from the study, I can do so up to a week after the focus group or interview, and that this data will be deleted where possible.
- I understand that data will be stored electronically on The University of Hertfordshire SharePoint with only authorised research staff having access, and will be kept for a period of 10 years, after which it will be destroyed.
- I voluntarily agree to take part in this study.

Name of participant: ….....

Signature of participant: .....

Date: .....

Name of researcher: .....

Signature of researcher: .....

Date: ….....

Appendix K: Individuals who draw on services and Carer Topic Guide (Phase 1b)

Welcome

Welcome participants and thank them for agreeing to take part in the focus group.

Ask participants to turn off their mobile phones. Explain the procedure in the event of a fire and give the location of the nearest toilets.

Moderator(s) introduce themselves and explain their roles.

Introduction (to be adapted if 1:1 interview)

As you know, the aim of meeting up today is to find out how you have found being assessed recently using a newly developed tool. For carers that are also here, we would value your input on how you feel the assessment may have had an impact on the individual you support, whether that be positive or negative. We want to hear your own views and experiences – there are no right or wrong answers. Please don't be afraid to say if you didn't think the assessment was helpful, or whether you thought it was useful. Also don't be afraid to disagree with others in the group, as well as agree with them. If you don't feel comfortable talking about something then that's absolutely fine, you don't have to give your views if you don't want to.

We're hoping to have a relaxed group discussion, so feel free to respond to me or other members of the group without waiting for me to ask you. To help us record what has been said, please try and make sure only one person talks at a time if possible.

Ask the group if there are any final questions before getting started, and address any questions asked.

Check that everyone in the group is happy for the recorder to be turned on then start the recorder.

Use simple language and refrain from using jargon where appropriate to aid understanding.

Use follow-up questions to clarify the participant's response or elicit additional detail when needed, for example:

- Could you tell me a bit more about that?
- And how did/does that make you feel?
- What did you think about that?

Icebreaker

Could we start by going round the room, introducing yourself and saying what town you live in.

Make it clear that this is optional. If some participants prefer not to introduce themselves (e.g., due to anxiety), then that's fine.

Topics and questions

1. **What did you know about frailty before someone talked to you about the frailty assessment?**
    - Had you heard the term before?
    - What do you think 'frailty' means?
    - Did you think of yourselves/the person they support as frail?

2. **What did you think about the frailty risk assessment?**
    - Who talked to you about the frailty risk assessment?
    - Did the information sheet about the assessment make sense?
    - Did they understand why the assessment was being done?
    - Did they understand what would be happening in the assessment?
    - Why did they agree to do the frailty risk assessment?
    - How did the person use the assessment with them?
    - Did they ask them about things that are important to them?
    - Did the tool ask about things that you think are relevant to frailty?
    - Was there anything that could have been better?
    - Was it easy to complete the frailty risk assessment?

3. **Was the frailty risk assessment helpful?**
    - What were you told about the results of the assessment?
    - Did the results make sense to you?
    - How did you feel about this? E.g., happy, worried
    - Did you talk with the person who did the assessment about any extra help or support?
    - Have you received any extra help or support? Do you want any?
    - Have you done anything differently after the assessment?
    - Would you want a frailty risk assessment again in the future or not?
    - Would you suggest to other people that they do the frailty risk assessment?

Close

Before we finish, is there anything else about your experiences of being assessed that would be useful for us to know?

Thank the participants for their time and for sharing their experiences and opinions.

Explain what will happen to the focus group data and how the findings will be used.

Appendix L: Health and Care Practitioner One Page Information Sheet (Phase 1b)

University of Hertfordshire UH

Information Sheet for Clinicians

We'd like to hear your thoughts on the Frail + Learning Disability Risk Assessment Tool

- We are a research team at the University of Hertfordshire, and we are inviting you to participate in a focus group.
- This focus group is for clinicians who have conducted assessments using the new Frail + Learning Disability risk assessment tool.
- It will involve answering questions about the training you received for the risk assessment tool, how you found using the tool in practice, and any other improvements or feedback you may have.
- This will help us understand what it is like to use the tool and how it might be improved.
- The focus group will take up to 1.5 hours and will either be via an online platform or face to face on Hertfordshire County Council premises.
- If you are interested in participating or would like more information, please contact Dominique Grohmann or Silvana Mengoni.

Contact details

Dominique - d.grohmann@herts.ac.uk
Silvana - s.mengoni@herts.ac.uk or 01707 284494

University of Hertfordshire UH

Appendix M: Health and Care Practitioner Topic Guide (Phase 1b)

Welcome

Welcome participants and thank them for agreeing to take part in the focus group.

Ask participants to turn off their mobile phones. Explain the procedure in the event of a fire and give the location of the nearest toilets.

Moderator(s) introduce themselves and explain their roles.

Introduction (to be adapted if 1:1 interview)

As you know, the purpose of today's discussion is to hear about your experiences of conducting assessments using the newly developed frailty risk assessment tool and gather your views on the tool so that it can be improved for future assessments. We are keen to hear everyone's views and to learn about differences in your experience, as well as similarities. There are no right or wrong answers. Please don't be afraid to offer negative as well as positive views of the risk assessment tool, and to disagree as well as agree with others in the group.

We're hoping for a relaxed group discussion, so feel free to respond to me and other members of the group without waiting for me to call on you. However, for the benefit of the transcriber, please try to make sure that only one person talks at a time if possible.

Ask the group if there are any final questions before getting started, and address any questions asked.

Check that everyone in the group is happy for the recorded to be turned on and then start the recorder.

Icebreaker

Could we start by going around the room, introducing yourself, where you are based and your role.

Topics and questions

1. **How does the tool differ to how you have previously considered risk of frailty for the service users you work with?**
    - How did you make judgements of risk of frailty beforehand? What helped make the decision? Prior knowledge of frailty
    - How does this assessment align with other assessments/clinical care you deliver?

- Do you feel that the screening of frailty risk fit within your role?

2. **How did you get involved in using the tool?**
    - Who approached you?
    - Why did you become involved?
    - Were the rest of your team involved too?
    - Who was involved in driving this forward?

3. **Can you tell me about the training you received for the tool and whether this prepared you to use the tool?**
    - Initial and ongoing training
    - Training content; format; timing; any ongoing training/supervision?
    - Any improvements?

4. **What did you think about the process of using the tool?**
    - Questions included in the tool and the 8 indicators
    - How the tool was used with service users + best interest assessments and capacity, and views on this process?
    - What helped/hindered tool use?
    - How many people did you use the tool with?
    - Was it similar to use with different service users? If not, what affected this?
    - How did the results align with your previous views about risk of frailty of your service users? – If different, what did you think about this?
    - Did the use of the tool fit easily with your routine work or did you have to change your usual way of working?
    - Any improvements to the tool?
    - Anything that might help inform roll-out across Herts and other counties?

5. **Did the tool support your clinical role?**
    - Is it feasible and worthwhile to use the tool in routine practice?
    - Was using the tool helpful? i.e., for your understanding of frailty risk and for overall health/social care provision for service users
    - Did risk of frailty relate to any characteristics of service users e.g., level of ID, medical conditions?
    - Have they done anything differently as a result of using the tool? E.g., treatment/support, if so, do they feel it has made an impact?
    - Is there anything you would differently now when working with service users?

- How do you think the tool was perceived by service users and carers?

Close

Before we finish, is there anything else about your experiences of conducting frailty risk assessments that would be useful to know?

Thank the participants for their time and for sharing their experiences and opinions.

Explain what will happen to the focus group data and how the findings will be used.

Appendix N: Health and Care Practitioner Covering Email (Phase 1b)

We are researchers from the University of Hertfordshire and we are interested in people's experiences of using the Frailty + Learning Disability Risk Assessment tool. If you would like to share your experiences with us, we would be grateful if you could read the attached information sheet and send an email to **s.mengoni@herts.ac.uk** with some very brief feedback.

In particular, we would like to know what was good about using the tool and what improvements might be needed. This might be related to finding out about the tool, training, the process of using the tool and if/how the tool supported your clinical role.

When providing feedback, please refrain from using names or other personally identifiable information of service users, carers, other staff etc. as although emails are kept safe, they can be intercepted.

Thank you in advance for your feedback. This will help us understand more about how the tool is used and how we could improve services for people with learning disabilities.

On behalf of the study team,

Silvana

Dr. Silvana Mengoni, PhD *(she/her)*
Joint Head of Centre for Health Services and Clinical Research
Senior Research Fellow - Dept of Psychology, Sport and Geography, University of Hertfordshire

Email: s.mengoni@herts.ac.uk
Tel: 01707 284494

University of Hertfordshire UH

Appendix O: Health and Care Practitioner Email Participant Information Sheet (Phase 1b)

Title of study: Assessing risk of frailty in individuals with learning disabilities: a pilot study

We would like to invite you to take part in our study. Before you decide, we would like you to understand why the study is being conducted and what it would involve for you. If you have any questions about the study, please contact the lead researchers, whose details are at the end of this information sheet. Your participation in this study is voluntary. If you do agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs (after accessing this website, scroll down to Letter S where you will find the regulation).

What is the purpose of this study?

Frailty has been defined as "a medical syndrome ... characterised by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death." (Morley et al., 2013). Studies have found frailty to affect individuals with a learning disability on average 20-30 years earlier than what is expected in the general population, which can lead to early mortality. It has been estimated that early deaths could be prevented if frailty is identified in the early stages and appropriate plans are implemented.

Currently there isn't a suitable tool to assess risk of frailty in individuals with learning disabilities and therefore we want to find out what it is like to use a new tool that has been developed by Hertfordshire County Council. The aim of the tool is to detect risk of frailty and make appropriate actions to reduce impact on physical health in the future.

We would like feedback from people who have been using the Frail + Learning Disability risk assessment tool to conduct assessments. We are interested to see how you have found using the tool and any suggestions or feedback you may have for further developments for the tool itself, resources and further training.

Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and to send us an email with your feedback. If you decide to withdraw from the study, this needs to be done no later than a week after you have sent your email in order for your information to be deleted. You do not need to provide a reason for your withdrawal.

What will happen to me if I take part and how long will it take?

Your involvement will involve sending us a brief email with your feedback about what was good about using the tool and what improvements might be needed. We anticipate this will take you no more than 10 minutes. By sending us this email, you are consenting to take part in the research. This means that you agree to, and understand, the information provided in this information sheet.

If you have any questions before providing your feedback, please email or phone us using the contact details at the end of this information sheet.

What are the possible disadvantages, risks or side effects of taking part?

We do not foresee any disadvantages or risks of taking part in the study.

What are the possible benefits of taking part?

Frailty is a significant factor when considering early mortality that could be prevented if adequate measures are taken and there currently isn't a suitable tool to assess risk of frailty in individuals with learning disabilities. By providing feedback on your experiences of using the tool, you are contributing towards the development of a tool that could be implemented in routine practice across the county and evaluated nationally to support individuals who may be at risk of frailty.

How will my taking part in this study be kept confidential?

We will transfer the information from your email into a password-protected document on the University of Hertfordshire SharePoint. We will not include your name, email address or other contact information in this document. Once we have done this, we will delete your email from our inbox.

Anonymised quotes may be used in reports and presentations, however identifying information will be removed.

Information will be stored electronically on The University of Hertfordshire SharePoint, and only authorised research personnel will have access to this. Data will be kept for a period of 10 years and then destroyed after this time.

Will the data be required for use in further studies?

The data obtained from this study will be analysed, and submitted for publication in an academic journal, and used in a grant application for a larger, longitudinal, study. We also intend to share the results of the study more widely, for example via talks, newsletters, press releases and social media. The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised.

Who has reviewed this study?

This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology ethics subcommittee who have approved it to be suitable. The UH protocol number is aLMS/SF/UH/05128(1).

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with **Dr David Wellsted** (contact details: University of Hertfordshire, College Lane, Hatfield, email: d.m.wellsted@herts.ac.uk), **Dr Silvana Mengoni** (contact details: University of Hertfordshire, College Lane, Hatfield, email: s.mengoni@herts.ac.uk, phone: 01707 284494) or **Dominique Grohmann** (contact details: d.grohmann@herts.ac.uk).

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix P: Agreement of assessments between first and second assessor (Phase 1b)

Assessor 1	Assessor 2 Low	Medium	High	Total	Kappa (se, z) p
Domain 1					
Low	3	5	1	9	0.28 (0.14, 1.97) p=0.025
Medium	2	7	1	10	
High	1	2	3	6	
Total	6	14	5	25	
Domain 2					
Low	5	2	3	10	0.39 (0.14, 2.8) p=0.0026
Medium	3	6	3	12	
High	0	0	3	3	
Total	8	8	9	25	
Domain 3					
Low	3	2	6	11	0.22 (0.13, 1.67) p=0.048
Medium	1	4	2	7	
High	1	2	4	7	
Total	5	8	12	25	
Domain 4					
Low	16	2	2	20	0.37 (0.16, 2.36) p=0.009
Medium	1	2	0	3	
High	1	0	1	2	
Total	18	4	3	25	
Domain 5					
Low	1	2	0	3	0.37 (0.17, 2.18) p=0.014
Medium	2	8	2	12	
High	0	4	6	10	
Total	3	14	8	25	
Domain 6					
Low	12	3	0	15	0.46 (0.18, 2.55) p=0.005
Medium	1	5	2	8	
High	0	1	0	1	
Total	13	9	2	24	
Domain 7					
Low	9	1	0	10	**0.65** (0.19, 3.26) **p<0.001**
Medium	3	11	0	14	
High	0	1	0	1	
Total	12	13	0	25	
Domain 8					
Low	4	4	1	9	0.06 (0.13, 0.48) p=0.314
Medium	5	4	5	14	
High	0	1	1	2	
Total	9	9	7	25	