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ORIGINAL ARTICLE

Practical applications of the NTG-EDSD for screening adults with intellectual disability for dementia: A German-language version feasibility study

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ABSTRACT

Background In this study, we evaluated the feasibility of using the German-language version of a recently developed screening tool for dementia for persons with intellectual disability (ID): the National Task Group – Early Detection Screen for Dementia (NTG-EDSD).

Method Some 221 paid carers of ageing persons with ID were asked to use the NTG-EDSD and report back on its utility and on 4 feasibility dimensions, and to provide detailed feedback on aspects deemed critical or missing.

Results All feasibility dimensions were rated good to very good, and 80% of respondents found the NTG-EDSD useful or very useful for the early detection of dementia. This highlights a high acceptability of this instrument by the main target group.

Conclusions The positive feasibility evaluation of the NTG-EDSD indicates the usability and adequacy of this instrument for application of early detection of dementia in persons with ID.

Introduction

Life expectancy for persons with intellectual disability (ID) has increased considerably during the last few decades. This increase is significantly larger when compared to the one for the general population (Bittles et al., 2002; Carter & Jancar, 1983; Janicki, Dalton, Henderson, & Davidson, 1999; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000; Strauss & Eyman, 1996). Therefore, dementia becomes a more prominent later-age health risk for persons with ID (Perkins & Moran, 2010; Strydom et al., 2010), but the assessment of the disorder in this population is still a matter of debate (Strydom & Hassiotis, 2003; Zeilinger, Stiehl, & Weber, 2013). In this study we evaluated the feasibility of the German-language version of a recently developed screening tool for dementia for persons with ID, the National Task Group – Early Detection Screen for Dementia (NTG-EDSD; Esralew et al., 2013; National Task Group on Intellectual Disabilities and Dementia Practices [NTG], 2013).[1]

Persons with ID by definition have a limitation in intellectual functioning (IQ < 70) and in social-adaptive behaviour, both of which originate in the developmental phase (Schalock et al., 2012). Due to these preexisting limitations, instruments for assessing dementia used in the general population are mostly not suitable for persons with ID (Deb & Braganza, 1999). These instruments are based on

the assumption of a statistically average premorbid cognitive functioning. Yet this assumption is not met by persons with ID, which makes early detection especially hard but nonetheless important for delivering early interventions. Furthermore, dementia can have a different clinical presentation in persons with ID than for those in the general population; for example, behavioural or personality changes generally occur more frequently and earlier in the course of the disorder (Ball et al., 2006; Janicki, Henderson, & Rubin, 2008; Strydom et al., 2010).

Dementia is one of the most prominent neuropsychological disorders related to ageing and contributes heavily to compromising the years lived with disability in the general population (World Health Organization, 2003). It is estimated that about 24 million people around the globe are affected by dementia, and this number is expected to double every 20 years through to 2070 (Ferri et al., 2005). Persons with ID have the same or even a higher risk of developing dementia (Janicki & Dalton, 2000; Strydom et al., 2010; Zigman et al., 2004). Yet, in some subgroups, especially in persons with Down syndrome, dementia is far more frequent and is known to have an earlier onset than for those in the general population (Holland, 1999; Janicki et al., 2008; Strydom et al., 2010). Thus, dementia and its early assessment are of great importance in persons with ID, as their life expectancy is increasing.

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Numerous ID-specific tools for the assessment of dementia exist (Zeilinger et al., 2013), but a consensus-based instrument for screening purposes has not yet been established. As the premorbid level of intellectual functioning differs widely among persons with ID, applying the same test to all persons with ID and interpreting it according to norm values is not recommended. A recommended approach is to establish an individual baseline assessment for persons who are at risk of developing dementia prior to the onset of the disorder. Periodic reassessments compared to the baseline on an individual level can yield indicators of symptoms of dementia (Aylward, Burt, Thorpe, Lai, & Dalton, 1997; Deb & McHugh, 2010; Kalsy & Oliver, 2005).

The NTG-EDSD used in this study was developed following these recommendations. Developed by a large panel of experts, translated in various languages, it was posited to be a starting point to establish a long-needed common assessment procedure for dementia in persons with ID. As the NTG-EDSD is intended to be completed by carers, it is deemed necessary that this group finds the instrument acceptable and feasible to use. Determining the applicability and feasibility of the NTG-EDSD for use by paid carers and proposing changes to strengthen the instrument's usability was the main aim of this study.

Methods

Participants

The total sample consisted of 221 paid carers[2] providing direct support to persons with ID, including 173 carers from Austria and 48 from Germany (77.7% women). A total of 95.5% had German as their mother tongue. Ages ranged from 19 to 65 years, with a median (*Mdn*) of 37 and an interquartile range (IQR) of 20. Years of experience in working with persons with ID ranged from 0.5 to 30 years (*Mdn* = 8, IQR = 10.08). The carers knew the person with ID for whom they completed the NTG-EDSD for a minimum of 0.5 and a maximum of 26 years (*Mdn* = 4.75, IQR = 6.91). They worked with the respective person a minimum of 0.25 and a maximum of 60 hours per week (*Mdn* = 20, IQR = 20). Nearly two thirds of the sample (66.4%) had experience in working with persons with dementia, and 69% indicated that they had very little or no experience in completing screening instruments like the NTG-EDSD.

Materials

NTG-EDSD

The NTG-EDSD is an informant-based administrative rating tool for assessing changes in cognitive and adaptive functioning associated with dementia in persons with ID. It is not meant to provide a diagnosis or be used as a clinical screening. It was developed in a thorough procedure by a large panel of experts (Esralew et al., 2013; NTG, 2013) and was intended to complement screening requirements for the general population under the National Plan to Address Alzheimer's Disease in the United States (U.S. Department of Health and Human Services, 2012).[3] The NTG-EDSD can be downloaded cost free from http://aadmd.org/ntg/screening. Available language versions of the NTG-EDSD include Dutch, English, French, Greek, Italian, Japanese, Spanish, and the German version developed in this study.

The NTG-EDSD consists of five sections: (a) demographic data; (b) general health and function items; (c) an adaptation of the Dementia Screening Questionnaire and Interview for Intellectual Disabilities (DSQIID; Deb, Hare, Prior, & Bhaumik, 2007); (d) an adaptation of the University of Illinois at Chicago's Longitudinal Health and Intellectual Disability Survey (Rimmer & Hsieh, 2012), which is composed of a listing of a variety of chronic health conditions; and (e) further information, which consists of an item on medication, a place for further remarks, information on next steps/recommendations, and information on form completion.

Feasibility questionnaire

A questionnaire for assessing the feasibility of the NTG-EDSD was especially developed for this study. It contained three parts. The first part included basic information about the respondent and about their relationship with the person with ID for whom they completed the NTG-EDSD. The second part comprised the items of the feasibility scale. In the third part respondents were asked about general aspects related to the completion of the NTG-EDSD, including the time needed for completing the instrument, sources of information used, how many questions in the NTG-EDSD they skipped, and about their opinion on the general usefulness of the instrument. Additionally, they were asked to rate on a 5-point Likert scale (1 = *not at all*; 5 = *very much*) whether using the NTG-EDSD in their organisation on a routine basis was, on the one hand, meaningful and, on the other hand, possible from an organisational perspective.

The dimensions and items of the feasibility questionnaire were chosen based on two feasibility theories (Andrews, Peters, & Teesson, 1994; Slade, Thornicroft, & Glover, 1999) and the feasibility dimensions listed in the Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (CAPs-IDD; Zeilinger, Nader,

Brehmer-Rinderer, Koller, & Weber, 2013). The final feasibility questionnaire consisted of 21 items assessing the dimensions applicability, acceptability, practicality, and relevance. A 5-point Likert scale was chosen as the response format (1 = *do not agree at all*; 5 = *totally agree*).

In order to keep the questionnaire short and user-friendly, but collect the most relevant information, free-text remarks could be given to some, but not all, feasibility items (see Table 1). Those items deemed as the most important ones to ameliorate the NTG-EDSD were chosen for further remarks. Respondents could specify the section(s) and question(s) in the NTG-EDSD their rating related to, and/or include free-text comments.

Procedure

Translation of the NTG-EDSD

A parallel-blind technique followed by a back-translation method was used (Behling & Law, 2005) to translate the NTG-EDSD from English into German. Six experts in intellectual disability, clinical psychology, and/or patient care were involved: four persons from Austria, one from Germany, and one from the United States. The translation process followed three steps. First, three persons independently translated the NTG-EDSD from English into German. Second, a bilingual expert performed a back translation to English. Translation discrepancies were discussed and resolved conjointly. Finally, two additional persons checked the translation independently, and a final version was produced in cooperation with the original translators.

Data collection

Data were collected from May to August 2013 in all nine provinces of Austria and two provinces of Germany. In Austria, 38 umbrella organisations providing residential facilities for persons with ID were invited to collaborate. Of these 38, 31 (82%) umbrella organisations with over 60 different residential facilities participated in the study. In Germany, data collection was embedded into an ongoing project on ID and dementia. The project took place in three large residential facilities for persons with ID, two of them in North Rhine-Westphalia and one in Saxony.

Participating residential facilities asked their direct support staff to autonomously act as respondents of the study. The research team had no influence on the selection of respondents. As it was up to the organisation to nominate carers to fill out the forms, no response rate can be given on the respondent level. In total, 221 questionnaires, 173 (78.3%) from Austria and 48 (21.7%) from Germany, were returned.

Participants first completed the NTG-EDSD for one ageing person with ID whom they had known for at least six months. Afterwards, participants completed the feasibility questionnaire in order to evaluate the NTG-EDSD. The feasibility questionnaires were returned either by email or by postal mail. To maintain confidentiality, the NTG-EDSD was not returned, but remained in the respective facilities. This was required so as to guarantee total anonymity to the persons with ID.

Although no formal ethical approval was obtained for this study, it was conducted in accordance with the ethical standards of the American Psychological Association (APA) in the following ways. First, the researchers provided participating facilities with information sheets, which were handed out to interested carers. In these information sheets, we described the study's goal, background, and procedure. We also explained that participation was voluntary, that participants' data would be stored securely and anonymously, and that they could contact the project coordinator at any time. Second, informed consent from participating carers was gathered verbally (in person or via telephone) or via email. The study design precluded obtaining consent from the adults with ID, as only the anonymised data about the participating carers as well as their opinions about the feasibility of completing the NTG-EDSD were relevant for this study. So that we did not compromise the anonymity of the adults with ID, we did not collect the data that appeared on the NTG-EDSD, as the adults reported on could have been identified by select characteristics.

Data analysis

Most data (including demographic data, the single items of the feasibility questionnaire, and some details on the completion of the feasibility questionnaire) were not normally distributed and/or contained outliers. Therefore median values (*Mdn*) and interquartile range (IQR) were used for examining those data. Mean values were used for examining feasibility scales, and Cronbach's alpha was applied for computing internal consistency. To examine the influence of carers' prior experience with dementia and screening tools on the feasibility ratings, Spearman rank correlations (r_s) were used. We followed the recommendation of Cohen (1988) in interpreting the results.

Initially, latent Dirichlet allocation (LDA; Blei, Ng, & Jordan, 2003), a generative probabilistic model, was used to group free-text comments by estimated topics. Due to sparse data, estimated distribution of topics was unstable and could not be reliably used for further examination. Therefore, instead of using LDA, free-text comments were independently hand coded by two researchers.

Table 1. Ratings of single items of the feasibility questionnaire.

	Frequencies in %					
	1: Do not agree at all	2	3	4	5: Totally agree	*Mdn*
Applicability						
The questions allow an accurate representation of the person	3.2	19.1	40.5	26.3	10.9	3
The response format allows an accurate representation of the person	3.6	25.9	41.8	20.5	8.2	3
Carers have sufficient experience with persons with ID to complete questionnaire	1.4	3.2	9.7	45.6	40.1	4
Carers have sufficient information about the person with ID to complete questionnaire	1.4	2.8	13.4	32.6	49.8	4
Carers have sufficient medical knowledge to complete questionnaire	4.2	10.6	27.8	29.2	28.2	4
The effort needed to complete questionnaire is adequate[a]	1.4	8.3	16.3	36.3	37.7	4
Acceptability						
Questions violate privacy[a,b]	57.2	27.0	7.9	6.0	1.9	5[b]
Questions are comprehensible[a]	5.5	3.2	10.5	31.0	49.8	4
Instruction is comprehensible	2.8	3.7	6.6	25.7	61.2	5
Instruction is sufficient	2.8	5.6	7.0	28.8	55.8	5
Questions are unambiguous[a]	4.1	7.8	10.0	32.0	46.1	4
Layout is suitable	1.9	6.1	25.9	37.3	28.8	4
Practicality						
Complicated[b]	48.8	24.9	13.4	10.1	2.8	4[b]
Amount of time needed for completion is adequate	2.3	8.7	12.9	39.4	36.7	4
Amount of time needed for reading instruction is adequate	2.3	7.0	16.2	34.0	40.5	4
Using the questionnaire for periodic reassessments would be realisable	2.3	3.7	13.0	26.8	54.2	5
Relevance						
Aspects are missing[a,b]	39.5	28.5	12.0	11.0	9.0	4[b]
There are unnecessary aspects[a,b]	65.0	22.2	8.4	1.4	3.0	5[b]
The purpose of the questionnaire is clear	1.4	4.6	8.3	32.1	53.6	5
The significance of the questions in relation to the purpose is clear	1.8	6.0	11.1	37.3	43.8	4
Using the questionnaire for periodic reassessments would be meaningful	3.2	6.4	15.6	24.3	50.5	5

Note. Items were rated on a 5-point Likert scale. Higher values represent better ratings.
[a]Further free-text remarks could be given.
[b]Questions were recoded. The medians given are already recoded.

Discrepancies were discussed until total agreement was reached.

Results

Details on the completion of the NTG-EDSD

Time needed to complete the NTG-EDSD ranged from 10 to 120 minutes ($Mdn = 30$, $IQR = 25$). As to sources of information other than their own knowledge/experience, 95% of the respondents used written documentation and files about the person with ID, 76.2% asked colleagues, 28.2% questioned the person with ID, and 11.1% used other means of information. In total, 74 respondents (33.5%) were not able to complete every question in the NTG-EDSD. Out of these, 35 respondents skipped fewer than five questions, 18 skipped five or more questions, and 21 did not indicate the amount of questions they omitted. Reasons for omitting questions included the carer did not have enough information about the person with ID ($n = 38$), the questions were unclear ($n = 15$), the question or the response format was not adequate to describe the person ($n = 13$), and some questions about communication could not be answered for persons without expressive language ($n = 4$).

Regarding the ratings on the general usefulness of the NTG-EDSD, 82.9% of the respondents deemed it useful or very useful for its intended purpose, the early detection of the symptoms of dementia. Furthermore, 71.8% deemed it useful or very useful for the early detection of general health problems, and 68.2% deemed it useful or very useful for a structured documentation of the general health of the person. Carers found it very meaningful to use the NTG-EDSD on a routine basis ($Mdn = 5$, $IQR = 2$), and they found it very possible from an organisational perspective ($Mdn = 5$, $IQR = 1$). There were only nine respondents who indicated that the completion of the NTG-EDSD was too much effort.

Feasibility ratings and influence of prior experience

Cronbach's alpha of all feasibility scales were satisfactory and are depicted in Table 2 along with the mean values of the scales. All values indicated good to very good ratings. Median values of single feasibility items showed similarly good or very good ratings and are depicted in Table 1.

Prior experience with dementia showed a small relation to the total feasibility scale ($r_s = .12$, $p = .08$) and the subscale applicability ($r_s = .22$, $p = .001$). Prior experience with screening tools showed a small to medium relation to the subscale applicability ($r_s = .16$, $p = .022$). In all these cases, respondents with more experience gave better ratings. Correlations with all other subscales were $< .1$, and are therefore negligible.

Table 2. Internal consistency of feasibility scales.

	Number of items	Cronbach's α	M (SD)
Total scale	21	.91	4.04 (0.6)
Applicability	6	.79	3.72 (0.68)
Acceptability	6	.73	4.17 (0.7)
Practicality	4	.74	4.08 (0.81)
Relevance	5	.8	4.24 (0.75)

Free-text comments

The respondents indicated that some of the questions in the NTG-EDSD violated privacy, were ambiguous, incomprehensible, or not necessary (see Table 3). The two aspects that were mentioned most frequently as being problematic were "language and communication" in Section 3 of the NTG-EDSD and "chronic health conditions" in Section 4. Respondents indicated that the problem with the first aspect was related to persons with ID who have no expressive language. Problems with the second aspect, the whole of Section 4, were related to a lack of medical knowledge and difficulty in understanding medical terms, as well as to the response format. As to the latter, the large gap between "condition diagnosed in last 5 years" and "lifelong condition" was indicated as problematic (e.g., how to rate a health condition that was diagnosed more than 5 years ago but was not a lifelong condition?). Furthermore, some health conditions included in Section 4 were deemed unnecessary for a dementia screening, and the use of IQ values for classifying the level of ID was criticised (as they were not relevant in the Austria/German services context).

There were 44 persons using free-text comments to suggest one or two missing aspects of the NTG-EDSD.

Those mentioned more than once included more categories in the response format ($n = 18$), adequate questions for persons with severe ID and/or without expressive language ($n = 6$), in-depth description of the person with ID including family history related to dementia ($n = 6$), more behaviour-related aspects ($n = 4$), improvements of the person with ID ($n = 3$), current mental health status ($n = 2$), and more activities of daily living ($n = 2$).

Discussion

This first feasibility study of the recently developed NTG-EDSD showed promising results with respect to use in German-speaking areas. All four feasibility dimensions were rated above the scale's average by paid carers. Over 80% of respondents found the NTG-EDSD "useful" or "very useful" for applications in the early detection of dementia, which highlights a high acceptability of this instrument by the main target group. Carers found it both meaningful and possible from an organisational perspective to use the NTG-EDSD on a regular basis in their respective organisations. On average, both questions were rated with the best category possible. This finding shows the adequacy of the NTG-EDSD when used in the context of organisations providing living facilities for persons with ID, an environment where time is often limited and carers tend to have a heavy workload.

Most carers used written documentation to complete the NTG-EDSD, and over two thirds used the knowledge and experience of colleagues. Therefore, when

Table 3. Critical aspects mentioned by carers in free-text comments.

Section in NTG-EDSD	No. of question	Question	Violation of privacy	Incomprehensible	Ambiguous	Not necessary
		The whole NTG-EDSD	3		1	
1	1–7	Personal and demographic information	3	1		1
1	8	Level of ID		1		3
2	11	Change in physical health		1		
2	15	Seizures		2		
2	16	Diagnostic history		1		
2	17	Reported date of onset of MCI/dementia			2	
3	19	Activities of daily living	1		1	
3	20	Language and communication		1	5	
3	21	Sleep-wake change patterns			1	
3	22	Ambulation		1		
3	23	Memory		1	2	
3	24	Behaviour and affect		2	1	
3	25	Adults' self-reported problems		1	3	1
3	26	Changes observed by others			2	1
4	27	Chronic health conditions		5	2	5
5	28	Medication	3			
5	29	Comments related to other notable changes or concerns			2	
5	30	Next steps/recommendations		1		

Note. Cell entries represent frequency of mentioning. ID = intellectual disability; MCI = mild cognitive impairment.

completing the NTG-EDSD, we recommend the use of available documentation on the person with ID, and working on the form in a team of carers (preferably involving carers with longer-term knowledge of the individual being screened). A consensus approach with multiple informants identifying issues and target behaviours can be most valuable, especially if the individual is enrolled or functions in several services over the day (e.g., work, residence, travelling).

Besides this overall very promising evaluation, there were some critical comments mentioned by the carers. These comments are especially useful for proposing changes to the NTG-EDSD or adapting its instructions and item definitions for country-specific applications.

Suggested adaptations to the NTG-EDSD

We recognise that the instrument may have varied applications, depending upon national or agency-specific data requirements and needs of diagnosticians who will use the screening data to pursue further queries. After carefully considering the comments of the carers, we propose six potential areas for adaptations (via omission or addition) to the NTG-EDSD:

(1) Omitting the use of IQ levels for indicating the level of ID when national conditions do not require these data.
(2) Including "current mental health status" in Section 2.
(3) Including an item on family history related to dementia.
(4) Including questions for persons with severe ID and/or without expressive language.
(5) Providing a glossary of medical and other terms.
(6) Adding a category or altering the designation in the responses in Section 4 between "diagnosed in last 5 years" and "lifelong condition" (possibly "diagnosed from 5 years to childhood").

Limitations

Several factors may be considered as limiting the applicability of our findings. One was that the feasibility study was conducted using the German-language version of the NTG-EDSD and as such contained some items developed for specific use in the United States; only later were these items recognised as having limited face validity with respect to the Austrian/German context. Some items could even appear intrusive in select European contexts, and this may have contributed to carers indicating that some of the items violated privacy. Yet the American NTG, which issued the NTG-EDSD,

permits country-specific alterations to suit program and service options listings and masking of items that may be in conflict with prevailing norms or practices.

Another limitation is that we did not collect the data on the NTG-EDSD forms. Analysing these data (e.g., in relation to missing items) would have allowed more detailed insights into the feasibility of the form. We were unable to collect these data due to limitations in time, personnel, and funds, but studying the actual NTG-EDSD forms should be a worthwhile goal for future studies.

Another factor was that the data collection processes differed between Austria and Germany. In Germany, the queries to carers were embedded into another study on dementia, with carers having been used to working with a dementia-specific questionnaire, whereas in Austria, it was a stand-alone study. Also, direct support staff are commonly not experts in dementia assessment, and found some of the items challenging. Consequently, some recommendations or critique have to be regarded with caution. Furthermore, respondents were participating in this study voluntarily; therefore, the gathered data could lack representativeness.

Lastly, when the study was conducted, the NTG had not yet issued its manual for the instrument. Consequently, the carers did not have the benefit of detailed instructions or definitions when using the NTG-EDSD.

Implications of the study: Practice and research

When the NTG-EDSD was translated initially into German, the instrument was shown to have high utility and helped focus much diverse data related to age-associated decline and health issues into a single palate. This permitted staff to better link the diverse presentation of behavioural and functional phenomena related to a possible dementia and to warrant a more formal assessment for dementia. The critical aspect gleaned from this study was the value of a more detailed user manual that would provide definitions of behaviours and conditions, which may be otherwise unfamiliar to carers. A country- or regional-specific manual would provide the basis for describing and identifying selected items for particular scrutiny and also enable the carers to be more attentive to changes and ancillary functions that should be noted and reported.

Conclusion

The highly positive feasibility evaluation of the NTG-EDSD supports the usability and adequacy of this instrument for the early detection of dementia in persons with

ID. Considering the recent development of this instrument, further evaluation concerning other characteristics of the NTG-EDSD is needed, but it has the potential to become a valuable and internationally usable instrument for the early detection of dementia in persons with ID.

Author note

An earlier iteration of this paper was posted on the website (http://www.aadmd.org/ntg) of the National Task Group on Intellectual Disabilities and Dementia Practices ("the NTG") for informational purposes in order to gain comment on and shape further work using the NTG-EDSD by NTG members and users of the NTG-EDSD. No other peer-reviewed version of this paper, in any iteration, appears in any other publication.

Notes

1. The German-language version is essentially identical to the original English-language version. The only difference is in items that vary due to country-specific social care condition categories. The core behavioural and functional items, as well as the DSQIID, remain identical.
2. Paid carers in this context are staff employed by services agencies to provide care and support to agency clientele with an ID.
3. The NTG-EDSD was originally developed for applications in the United States in response to aims found in two documents, "'My Thinker's Not Working': A National Strategy for Enabling Adult with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports" (NTG, 2012; Goal #4: "Encourage provider agencies in the United States to implement screenings of their older-age clientele with an intellectual disability who are at-risk of or affected by dementia") and the "National Plan to Address Alzheimer's Disease" (U.S. Department of Health and Human Services, 2012; Strategy 1.B: Ensure timely and accurate diagnosis, and Action 2. B.2: Identify and disseminate appropriate assessment tools). When issued, its purpose was for it to be used as an administrative screen of adults at risk for dementia and any data collected to be used as part of subsequent assessment or diagnostic event. It was also to be used as the "cognitive assessment" event for adults with ID as part of the mandated annual wellness visit under the Affordable Care Act in the United States. Its use in other countries was dependent on national or local needs and applications, and it was recognised that some items tangential to screening could be omitted or adapted.

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